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ABSTRACT

This report reviews projects funded during 1989 within the Children with Severe Disabilities (CWSD) component of the Australian Government Special Education Program. The review examined four aspects: (1) identification of those currently receiving services through CWSD funds; (2) description of the type of programs being funded; (3) the role of CWSD funds in the lives of young children and their families; and (4) identification of critical issues for the CWSD subcommittee. Findings included the following: most children being served are 24 to 48 months of age living at home; most projects are initiated by community groups and provide early intervention educational programs; and most families feel that, without the CWSD-funded projects, their children would have no access to appropriate educational programs until school age. The review also identified issues in the areas of CWSD program administration, adequacy of funding for individual projects, conditions of employment, a need for ongoing professional development, and parental need for information and skills to ensure long-term access for their child to high quality programs and services. (Contains 16 references.) (DB)

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Special Education Program, 1989

Review of
The Children With Severe Disabilities Program

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RECOMMENDATIONS

1. Involving the parents in teaching and decision-making

1.1 The CWSD Sub-committee, to see if any procedures can be implemented that will help to maximise the impact of CWSD funds on parents and families, as well as on the child who has a disability.

1.2 Use of an integrated interdisciplinary staff
The CWSD Sub-committee should endeavour to identify strategies that will facilitate and encourage project staff, both teachers and therapists, to seek to coordinate their services more effectively.

2. Who is receiving help from the projects funded by the CWSD Program?

2.1 Age

In the light of uncertainty and inconsistency in the application of eligibility requirements across projects in different types of settings and in different regions of the state, it is recommended that specific guidelines be formulated to define the age of children who are eligible to participate in CWSD projects, particularly where alternative schooling options are available.

2.2 Disability: type and level of severity.

It is recommended that the Committee identify clear and simple guidelines that can be used by staff implementing CWSD projects to identify children whose impairments are severe in nature and who are therefore eligible to participate in projects.

2.3 Location of projects and children

2.3.1 Children living at home.

In view of the difficulties that many of the projects reported in this review in relation to finding staff and resources to support a home-based program, it is recommended that the Sub-committee should give priority to programs that provide centre rather than home-based services, but ensure that sufficient resources are available for some flexibility, where families are unable to attend a centre.

2.3.2 Children in long day or child care centres.

It is therefore recommended that the Sub-committee review the needs of children with severe disabilities and their families for services of a child care nature, with consideration being given to providing seeding grants to support the establishment of such services in existing centres or in new services specifically catering for this group of children and their families.

2.3.3 Children in long-term residential care

It is suggested that the Sub-committee review its priorities in relation to funding projects within long-term residential care units, to ensure that it is not supporting programs which, in some respects, are outmoded in terms of current community standards; or programs operating in facilities operated by large organisations which should have access to funding to support early intervention services from within their own resources.

2.3.4 Minority Group Representation

It is therefore recommended that the Sub-committee specify in Program guidelines that, on the basis of equity, organisations providing services at local, regional or State levels ensure that all families who have children who are eligible to take part in CWSD projects receive information about the service and are encouraged, and if necessary, assisted to take full advantage of these opportunities for their children.

3. What form of service is being provided or supported by CWSD funds?

3.1 Priority areas

It is suggested that the Sub-committee should continue to support community-based program initiatives, since they generally provide services where none exist, and, in most cases, actively involve parents of the children in many aspects of the teaching program. However, in relation to CWSD projects located within facilities operated by government departments and large charitable organisations, the Sub-committee should give consideration to providing funds to support new initiatives, as a seeding function only. Once the need for the service is recognised, the umbrella organisation should accept financial responsibility, in line with changing needs and community expectations.

3.2 Programs involving parents

3.2.1 It is therefore recommended that the Sub-committee consider the following procedures to ensure that parents are involved in CWSD projects as fully as possible.

3.2.2 Include questions about parental involvement in the CWSD application forms.

3.2.3 Support professional development activities concerned with parental involvement.

3.2.4 Continue to give priority in funding decisions to programs that actively involve parents, and

3.2.5 Consider the introduction of a Newsletter or similar information sheet that could provide a means of informing projects about matters related to the effective involvement of parents in their children's programs.

3.3 Practical solutions to student needs

It is therefore recommended that the Sub-committee consider developing a range of procedures to ensure that information is made available to all projects about resources available within various government departments; and about successful projects, assessment techniques, teaching programs, data collection instruments and so on; opportunities should also be provided to enable staff to visit successful projects and to attend relevant inservice courses, conferences and other professional development activities; the CWSD field officers should continue to be available to provide direct assistance to projects that require help.

3.4 Program Operation and Implementation

The Sub-committee is urged to ensure that the level of funding provided to projects, particularly those associated with smaller, community-based organisations, is maintained at a level that is sufficient to keep the service viable and does not result in an excessive burden on staff responsible for its operation.

3.5 Limited or inappropriate preservice training among teachers and aides

It is strongly recommended that the Sub-committee support any initiatives associated with the provision of in-service or on the job training for teachers and, more particularly aides, who lack training and experience in early special education.

3.6 Staff conditions of appointment

It is recommended that the Co-ordinating Committee provide guidelines to all projects about salaries and conditions for all staff, particularly teachers and aides.

3.7 Unsuitable premises

It is recommended that the Sub-committee develop a set of guidelines for standards to be met by all projects in relation to premises in which the project is located: information should also be provided to new projects about licensing requirements, insurance, health and other safety standards.

It is recommended that the Sub-committee identify procedures that could be implemented to ensure that the members of Management Committees are kept informed about aspects of the programs offered by their organisation that are associated with the delivery of high quality programs to children and their families.

4. Are there any issues concerning the operation of the CWSD Program that should be drawn to the attention of the Sub-committee?

4.1 Adequacy of CWSD funds

It is recommended that the Sub-committee ensure that the funds allocated to projects are sufficient to enable these services to remain viable. Where appropriate, smaller projects should be encouraged to coordinate their services with other, similar programs within a district or region, to ensure that a network of support is available for staff working in isolated circumstances, a larger pool of resource materials and more efficient administrative arrangements. Where funding is to cease, consideration should be given to providing a period of advanced notice: for example, a minimum of 12 months warning of termination of funds.

4.2 Timing of payments

It is therefore recommended that the Sub-committee ensure that both formal notification of funding approval and payment of the grant is completed as early as possible in each funding cycle.

4.3 Assistance with preparation of CWSD applications

It is recommended that the Sub-committee ensure that assistance and, where necessary, training is provided to help project representatives complete CWSD funding applications and that the forms are easy to follow and simple to complete.

4.4 Integration of Early Special Education and CWSD Programs.

It is therefore suggested that the Sub-committee consider amalgamating the two programs concerned with young children with disabilities to a single program, with a component to be earmarked for projects providing services for the priority areas of children with severe disabilities in the years prior to school entry and for students in the 0-18 years age range who are denied access to appropriate educational services as a result of severe disability.

CHAPTER 1

INTRODUCTION

This report is concerned with a review of projects funded during 1989 within the Children with Severe Disabilities (CWSD) component of the Commonwealth's Special Education Program. The objectives of the Special Education Program, overall, are to improve the educational participation and outcomes of children with disabilities or children in institutions. A specific component of these objectives concerns the provision of assistance to enable children with severe disabilities to participate in education programs, and it is with this element of the Special Education Program that the report is concerned. Organisations eligible to participate in the CWSD Program include government and non-government education authorities, religious organisations, charities, parents, parent groups, and other State instrumentalities. Responsibility for determining the criteria for eligibility for participation in the Program (i.e. criteria for identifying children with severe disabilities) is vested in State Special Education Coordinating Committee, but Program Guidelines state that participating students should be in the age range 0-18 years (DEET, 1989, p 62). This report is concerned with CWSD-funded projects that provide services for children who are below school age; (i.e, 0-6 age range (DEET, 1989, p.58).

1. THE CHILDREN WITH SEVERE DISABILITIES PROGRAM; AN OVERVIEW

1.1 Background

Following the establishment of the Commonwealth Schools Commission in 1973, the Commonwealth Government, in cooperation with State government and non-government authorities, has developed and implemented a number of initiatives designed to "strengthen the capacity of schools to meet the challenges they face" (DEET, 1989, p.1). A range of general recurrent, capital and specific purpose programs have been funded by the Commonwealth to achieve this goal. Among the specific objectives for schooling identified by the Commonwealth in guidelines for its programs in 1989, reference is made to the improvement of participation and achievement among students who are "disadvantaged as a consequence of ethnicity, Aboriginality, socio-economic circumstances, geographic location or physical or intellectual ability" (DEET, 1989, p.1). The CWSD Program is one, among a number of Commonwealth Government programs for schools, that contributes to the achievement of these objectives, with its specific focus on the needs of children who are disadvantaged as a result of severe disabilities, particularly in the areas of physical and intellectual development. Responsibility for the administration of this and other Commonwealth Programs for schools lies with the Department of Employment, Education and Training (DEET). At the State level, the administration of the CWSD Program is carried out on the advice of a co-ordinating committee representing relevant government and non-government agencies.

1.2 The CWSD Program

The CWSD Program was introduced into the Commonwealth Government's programs for schools in 1981. A survey of special education in Australia, commissioned by the Commonwealth (Andrews, Elkins, Berry & Bunge, 1980) had identified 1100 children with severe disabilities, many of whom were living in long-term care facilities operated by State Health authorities, who were receiving inadequate educational services or no education at all. At the time that the survey of special education was carried out, the Commonwealth had already introduced the children in Residential Institutions (CIRI) Program, as a means of providing supplementary support for the education of children and adolescents living in residential institutions who lacked the experiences and help normally provided by families for their children. Some of the CIRI programs operated in facilities for children with severe disabilities. However, funds provided through the CIRI Program were intended to enhance and complement the education received at school by children living in residential care. The aim of the new program, known initially as the Severely Handicapped Children's Program (SHCP) was to enable the appointment of "teachers, therapists and aides to provide suitable educational activities for those severely handicapped children" (Commonwealth Schools Commission, 1981, p.392). An initial sum of $2.1 million (actual $2,472) was allocated to the new program and by 1984, this had increased to $3.55 million (actual $3.668). In 1989, the total allocation to the CWSD Program had increased to $4.408 million. Over this period, the annual allocation to New South Wales increased from $843.000 in 1981 to $1,490.000 in 1989. Initially, these allocations were based on estimates of the number of children in the age range 5-16 age population. However, by 1984, program guidelines stated:

> As in other areas of the Special Education Program, funds provided for the Severely Handicapped Children's Program may be applied to early intervention programs for children below school age. The Commission has agreed that an amount representing up to 10 per cent of the funds allocated under this program in 1984 should be used to provide services to severely handicapped children below school age in need of, but not receiving assistance through early intervention programs or receiving services which are inadequate in terms of the provisions made (Commonwealth Schools Commission, 1984, p.45)

By 1989, the basis for distribution of funds among the various States had become the number of children in the 0-18 age population (DEET, 1989, p.61),

1.3 Evaluation of the CWSD Program

From the start, the Commonwealth recognised the need for evaluation of the services funded through its various programs for schools. The need for evaluation of special education initiatives was highlighted in the recommendation of the Schonell survey of special education in 1979 (Andrews et al, 1980) that more applied research and evaluation be carried out into all aspects of the provision of special education for students with disabilities in Australia. In 1983, a review of the Special Education Program was commissioned by the Commonwealth (Ashby & Taylor, 1984) and a number of general problems associated with the operation of the Program were identified at this time. In addition, in 1984, an Advisory Group on Early Special Education was appointed to advise the Commonwealth on future policy, operations and directions for the recently introduced Early Special Education Program. The report of this group recommended that children in the age range 0-6 years continue to be eligible for inclusion in the SHCD Program (Andrews, 1985, p.41).

In 1983, a group from Macquarie University under the leadership of Professor James Ward carried out a review of the Children in Residential Institutions Program (Ward, Bochner, Center & Ferguson, 1984) and at the same time, a more detailed examination of this program was carried out in New South Wales (Ferguson & Ward, 1984). A replication of the census component of the 1984 CIRI review was replicated in New South Wales and Victoria in 1988 by Bochner and Ward (1989).

In 1984, the Working Committee of the SHCP Program in New South Wales accepted a proposal for an evaluation of the program in that State, to be carried out by Professor Ward and Cecile Ferguson from Macquarie University. The aim of this study (Ferguson & Ward, 1986) was to collect detailed information about the implementation of the Program, to obtain feedback from participants, to compile data about individual projects for the information of parents or other service providers and to provide basic information about this area of service for policy makers, particularly within the NSW Department of Education and its Division of Guidance and Special Education. The report of this evaluation (Ferguson & Ward, 1986) provides an interesting benchmark in relation to the aspects of the review that are also addressed in the study that is the subject of this report. Where relevant, reference will be made in the following sections of this report to information presented in the 1984 evaluation by Ferguson and Ward. However, it should be noted that the 1984 review covered all aspects of the operation of the SHCP Program, including its operation and administration, the implementation of direct service projects in terms of grantees, children and parents or guardians, and the elements of the program concerned with resources and staff development. In contrast, the present review focussed on direct service projects, their implementation and impact on children and families. A separate but related study has examined the provision of services for children with severe disabilities, as part of a survey of children and families who were receiving early intervention in the later months of 1989.

1.4 Review of the CWSD Program, 1989

1.4.1 Background to the proposal

In 1988, a proposal was made to the CWSD Program, under the research component of its funding arrangements, for a grant to carry out a review of the operation of the Program in relation to the provision of direct services for children. The proposal was prepared following advice from a group of colleagues who were actively involved in the provision of early intervention programs. The group who contributed to the initial proposal included Sue Bettison, Sandra Bochner, Joy Goodfellow, Sandra Leonard, Moira Pieterse and Penny Price. Colleen Hore also attended these preliminary discussions.

No review of the CWSD Prograqm in New South Wales had been carried out since the 1984 evaluation by Ferguson and Ward and over intervening years, the pattern of care and provision of educational programs, particularly in relation to young children with disabilities, had changed significantly. The number of children with disabilities admitted to long-term residential care in New South Wales had reduced. For example, the CIRI review (Bochner & Ward, 1989) reported that in 1983 there were 1302 children in residential care In New South Wales for reasons associated with intellectual impairment, while in 1988, this number had reduced to 867. At the same time, the number of early intervention programs and related services available in the State had increased (Pieterse, Bochner & Bettison, 1988); for example, in a survey of all services of an early intervention nature that was carried out in New South Wales in 1989, as part of studies that were carried out concurrently with this proposal, a total of 339 programs were identified, providing services for an estimated

5700 chidren. (A directory of these services is being compiled).

The proposal for the review included provision for structured interviews to be conducted with project staff during a series of visits to be made to selected projects funded in 1989 by the CWSD Program. To complement the information collected during these visits, a survey was to be carried out of families in receipt of early intervention services during the latter part of 1989. From the group of children identified in the survey, those who could be considered to have disabilities that were severe in nature would be identified. The responses of this group of children to the survey would be examined separately, when the results of the survey were compiled. These data would supplement information collected during site visits about the services provided for children with severe disabilities through the CWSD Program.

1.4.2 Aims of the Review

The broad aims of the study were:

1. to review the CWSD Program in terms of the operation of selected projects funded wholly or in part by CWSD grants (Chapter 5).
2. to examine the extent to which these projects comply with the CWSD Program guidelines and priorities; (Chapter 6); and
3. to evaluate the impact of CWSD funds on the services provided to young children with severe disabilities and their families (Chapters 6, 7 and 8)

It was anticipated that information collected in the study would provide the CWSD Program Sub-committee and the NSW Special Education Coordinating Committee with useful information about both the services that are funded under the CWSD program and about the operation of the Program. It would also enable the CWSD Sub-committee to receive feedback from grantees about funding arrangements and about the impact of CWSD funds on the services provided for children with severe disabilities by these agencies.

The more specific objectives of the study were:

1. to collect basic information about the children involved in projects funded by the CWSD Program: i.e. Who is receiving help from CWSD funds?

2. to collect basic information about projects funded by the CWSD Program: i.e. what form of service is being provided or supported by CWSD funds?

3. to examine the impact of CWSD Program funds on the projects involved: i.e. how important are CWSD funds to the projects receiving them?

4. to identify issues, major strengths and any problems associated with the operation of the CWSD Program: i.e. are there any issues that the Co-ordinating Committee and the CWSD Sub-committee should be aware of in relation to the operation of the CWSD Program?

Answers to these questions will be presented in the final Chapter (7) of this report and some recommendations will be made about issues that should be drawn to the attention of the CWSD Sub-committee.

1.4.3 The Research Team

Members of the Macquarie University research team who participated in the data-collection process included:

Sandra Bochner: Special Education Centre
Joy Goodfellow: Institute of Early Childhood
Moira Pieterse: School of Education,
Penny Price: School of Education,

Penny Price was responsible for the development of the interview form that provided the basis for data collection during site visits carried out for the Review. The interview format was based on procedures developed by Dr David Mitchell in a series of evaluations of early intervention programs in New Zealand (Mitchell, undated).

Elizabeth Sapir assisted in the analysis of data collected in interviews conducted during site visits and this report was written by Sandra Bochner. Members of the research team and written by Sandra Bochner. Members of the research team and representatives of the 27 programs that participated in the Review commented on the final draft of the report and their suggestions were incorporated into the final document.

1.4.4 The Context of the Review

As already noted the review of the CWSD Program was conducted in conjunction with two other, related studies. The first involved a survey of early intervention programs and services operating in New South Wales in the period June 1989 to June 1990. The second involved a survey of children and families associated with Early Intervention Programs in New South Wales in the period June to November, 1989. Separate reports are being prepared on these two related studies. However, reference will be made to information collected in these projects, as appropriate. The focus of this report is on the CWSD Study.

1.4.5 Format of this Report

In the following chapters of this report, the operation and administration of the CWSD Program is reviewed (Chapter 2) and the procedures followed in the review of the Program, including the sample and the data collection methods are outlined (Chapter 3). Results are then reported, first in terms of information obtained from CWSD records (Chapter 4) and then from data collected during site visits and interviews with project staff (Chapter 5). Material collected from interviewees about the operation of the CWSD Program, its strengths and weaknesses as well as its major impact on children and families, is then considered (Chapter 6). Finally, some conclusions are drawn about the operation of the Program and some recommendations are made about issues highlighted during the Review that should be brought to the attention of the Co-ordinating Committee (Chapter 7). A summary of the main findings of the study conclude the report (Chapter 8).

CHAPTER 2

THE CWSD PROGRAM: OPERATION AND ADMINISTRATION

In the following discussion, the operation of the CWSD Program is reviewed in terms of its aims, the procedures followed in its implementation and its pattern of funding. Where appropriate, comparisons are made with data reported by Ferguson and Ward (1986) from their earlier review of the program.

2.1 Aims

The stated aim of the CWSD Program is to support educational programs provided for children with severe disabilities who are living at home or in a residential care situation, with the object of helping the children to achieve their potential for independence and to build their self esteem (DEET, 1989, p.61).

2.2 Implementation

As with other Special Education Programs offered by the Commonwealth through the Department of Education, Employment and Training (DEET), the CWSD element is implemented through submissions made annually by eligible authorities and organisations for funds to support specific projects. Applications are usually invited through advertisements placed in local and regional newspapers at a date determined by the CWSD Sub-committee. The program is administered on the advice of the Co-ordinating Committee which is responsible for making recommendations to the NSW Minister of Education about CWSD grants to government and non-government agencies.

2.3 Program Guidelines

In its guidelines for the operation of the CWSD Program, DEET (1989) makes suggestions about the elements that should be included in applications for funding and in the priorities that will be followed in the assessment of proposals. For example, the 1989 Guidelines stated that program proposals should be based on clearly stated objectives and should include provision for appropriate assessment and evaluation procedures to ensure the effectiveness of the project. It is also stated that in recommending proposals for approval, the Committee will give priority to proposals concerned with the provision of assistance to children who receive inadequate levels of services, particularly those who live in isolated and rural areas. Programs that actively involve parents will also be given priority, together with those that involve provision of practical solutions to the learning needs of children with severe disabilities (DEET, 1989, p.62).

According to information set out in the administrative guidelines for the Program, funds may be used for salaries of teachers and other specialist staff, professional development of staff and parents, consultancy and advisory services, travel and transport of children, curriculum development, purchase of equipment and materials, and monitoring and evaluation of programs (DEET, 1989, p.48).

2.4 Applications for Funding

Each year, applications are made to the CWSD for a variety of different types of projects and from a number of different agencies and organisations. For example, in 1989, a total of 89 applications were received for a total sum of $2,895,361.00. Of this number, six were from institutions catering for groups of children, five for children living at home, 15 from school-based projects, four from agencies operating across the State, 50 from early intervention programs and nine for research projects. This review was included among these research applications. The submissions that were given highest funding priority by the CWSD Sub-committee were associated with institutions (5), individual children living at home (4), school-based projects (7), statewide projects (3), early intervention programs (40) and research proposals (3). The total sum involved is $1,332,614.00. The focus of this review is on projects provided for children in the 0-6 age range and it is not evident from these data which projects were for children in this age group, though it could be assumed that the 40 early intervention projects funded were for children in the 0-6 year age level.

It is interesting to compare this pattern of funded applications with the pattern of project approvals in the period 1981, 1985 and 1989. (Note: the figures in Table 2.1 for 1981, 1985 and 1989 include all CWSD projects approved for both children and adolescents; i.e. 5-16 years: 1981 and 0-18 years: 1985, 1989). From data set out in Table 2.1 it is evident that the percentage of individual child projects has reduced steadily from 1981, when they represented around 9% of all project funds, to around 1% in 1989. Projects in institutions represented around 29% of the funds allocated in 1981, but this increased to 42% in 1982 after information about the CWSD was distributed to eligible institutions (Ferguson & Ward, 1986), remaining at around that level to 1985. However, by 1989, the percentage of funds used in this way had reduced to around 20% providing some further evidence of a reduction in the number of children in residential care over the period 1985-1989.

TABLE 2.1 TOTAL FUNDS ALLOCATED BY CATEGORY OF PROJECT: 1981, 1985, 1989 (percentages)

Category of Project	1981(1)	1985(1)	1989
Individual child	8.8	8.1	1.5
Institutions	29.4	41.6	20.2
School based	7.5	5.8	4.0
Community teams	23.3	7.9	-
Early Intervention	-	23.6	55.5
TOTAL directed-services	69.0	87.1	81.2
Resource/Staff Development	24.0	12.0	14.8
Research	6.6	0.9	4.0
TOTAL other services	30.6	12.9	18.8

(1) SOURCE: Ferguson & Ward, 1980, 1986, p.21

Probably the most interesting change evident in Table 2.1, for the topic of this review, concerns the increase in funds allocated to early intervention projects over the period 1981 to 1989. In the 1981 round of funding decisions, no grants were made to early intervention programs, primarily because children under 5 years of age were not eligible to participate in CWSD projects. In 1983, these types of programs were declared eligible and by 1985, they attracted 24% of allocated funds and this percentage had increased to 55% in 1989.

COMMENT:

The CWSD Program has operated since 1981, as one element in the Commonwealth Government's provision of funds to support educational programs for children who are disadvantaged or disabled in some way. The Program operates through annual submissions which are submitted to a sub-committee representative of organisations, government and non-government, who are involved in the care and education of children with disabilities. Over the years of its operation, the pattern of participation of different types of services for children with severe disabilities has varied, with a marked increase in the number of early intervention programs in the period from 1985.

CHAPTER 3

THE CWSD REVIEW

In this chapter, the procedures followed in the review of the CWSD Program are considered and the method of data collection and analysis is described.

3.1 Methodology of the Study

The CWSD review can be described as formative in nature, since it is concerned with a program that is ongoing. In preparing the initial proposal for the study, some thought was given to procedures that could be used to obtain quantitative information about projects and their impact on children: for example, scores obtained by individual children on standardised tests (e.g. Griffith Scales) on criterion-referenced measures (e.g. Developmental Skills Inventory). However, on the basis of personal knowledge of various early intervention projects among members of the research team, it was evident that this approach would be difficult; for example, not all projects maintained consistent record over time, and where such data were recorded, a variety of test instruments were used, including both published measures and informal check-lists developed for use by a particular teacher. It was therefore decided that more qualitative information would be sought, with all material collected during site visits, carried out by at least one member of the research team. It was agreed that interviews would be held with key members of the staff at each site visited, using a structured interview format. This would enable some compilation of individual responses to specific questions, but would also provide for the collection of more qualitative data which would highlight specific issues associated with the operation of particular projects or groups of projects. This procedure, involving structured interviews conducted during site visits, was the primary method of data collection used in this study.

3.2 The Sample

A list of the agencies that had received funding from the CWSD Program during 1989 was obtained from the CWSD Sub-committee. Since the focus of the study was on services provided for children with severe disabilities under the age of six years, those services that had no clients in this age group were identified by CWSD Program administrative staff and these groups were excluded from the study. Because of constraints in terms of time available to visit programs and the distance of some services from the Sydney area, it was decided that the study would be based on a sample of services. Programs listed by the CWSD Program that catered for children under school age were identified and categorised in terms of prior knowledge of some services and, where no information was available, on program titles and the location of the administering authority (preschool, hospital or early intervention centre). On the basis of this information, seven categories of service types were identified, including early intervention programs, hospitals for children with severe disabilities, therapy or hospital-based programs, long day care, preschools and home-based projects. The number of programs in each category was then calculated. (See Table 3.1).

TABLE 3.1 DISTRIBUTION OF ALL PROJECTS (0-6 YEARS) FUNDED IN 1989 AND PROJECTS INCLUDED IN REVIEW SAMPLE BY LOCATION (PERCENTAGES)

Location	All Projects	Sample Projects
Early intervention centre	56	63
Residential care	10	11
Special school	2	-
Therapy service	17	7
Preschool	8	7
Long day care	5	7
Home-based	2	4

Four researchers were available to visit program sites, and it was anticipated that, either individually or, in the initial phase of the study, in pairs, visits could be made to approximately 24 sites. Using a table of random numbers, a sample of sites was selected, weighted roughly in terms of the proportion of each category of service identified on the CWSD list. An initial list of programs to be included in the study was compiled.

The research team met and examined the proposed sample list. It was agreed that services located outside the Sydney metropolitan area would be included in the sample, if at all possible. Moira Pieterse agreed to visit programs located in the areas around Bathurst and Newcastle. Joy Goodfellow was able to arrange a visit to services in the North Coast area and Penny Price agreed to visit programs in Wagga Wagga, Wollongong and Moree, if this could be arranged. Moira Pieterse, Penny Price and Sandra Bochner would visits sites in and around Sydney. The original sample list was therefore modified, to retain the proportion of the different types of programs initially identified, but with some substitutions, according to the projected travel arrangements that could be made by individual researchers. The 27 programs that were finally selected for inclusion in the study included almost all of the services funded by the CWSD Program that had children in the target age group and could be accessed by the team. A list of the programs included in the final sample is attached (see Appendix A) and their distribution, in terms of the information available at the time the sample was selected, is set out in Table 3.1.

It should be noted that two site visits involved discussions with staff from more than one program. At one large metropolitan service, the teachers in charge of two early intervention projects that operated in locations in neighbouring suburbs were interviewed. At another site, on the outskirts of metropolitan Sydney, staff were interviewed from three separate projects, located on neighbouring sites, that applied as one unit to the CWSD Program. The responses obtained from these interviews were included in the summary results. In all other cases where projects operated on more than one site, only one interview was held with a representative or representatives of the umbrella organisation. In addition, one metropolitan project selected as a sample site had ceased to operate at the time the review was conducted, but a discussion was held with the project co-ordinator about factors within the CWSD program that contributed to the closure. Another, rural project was selected for inclusion in the review but difficulties were encountered in finding a suitable time for a visit and, in the end, no interview was held. These two programs are not included in the list of sample sites

3.3 Procedure

Most information for the study was obtained during site visits and interviews conducted with program staff. However, useful data were also obtained from CWSD records.

3.3.1 CWSD Program Records

As part of the data collection process, information was collected from CWSD Program files about the programs included in the sample, in terms of the project for which funds were sought, the number of children that it was anticipated would be involved, their age range, the allocation of the grant in terms of salaries for teachers or aides, equipment, transport or travel, and so on. Details were collected for the period 1986-1989 for each of the 27 programs included in the study.

3.3.2 Structured Interviews

It was agreed that structured interviews would be conducted by at least one member of the research team with relevant staff during a visit to each of the 27 services identified. Initially, training visits were carried out by two members of the team, one of whom, Penny Price, was experienced in the use of the interview schedule (Mitchell, undated) through previous involvement in an evaluation of early intervention programs in New Zealand with Dr David Mitchell. Following at least one training visit, and after discussions were held by those involved in this phase of the data collection, visits were made to all sites by either one or two staff, according to availability. Most interviews were over two hours in length and, in all cases, those interviewed appeared to be willing to spend this time discussing the CWSD project.

Part of the research procedure developed by Dr Mitchell included sending a copy of the questionnaire to the interviewee, prior to the date of the visit, so he or she would be familiar with the questions that would be asked. In the CWSD study, this procedure was also followed. However, it was found that some recipients of the interview schedule prepared written responses to the questions prior to the interview and it became apparent that the interview form could also be used as a questionnaire, comprising a number of open-ended questions. The form was therefore reorganised, with space left between each question, and staff to be interviewed at each subsequent site visit were invited to prepare written answers, prior to the visit. The completed form was collected at the time of the visit when the interviewer was able to review each question in the completed form, clarify any areas of uncertainty or collect additional information, as appropriate. In some instances, where only one interviewer was involved, discussions with project staff were tape recorded so that there was less pressure to collect written information during the visit. These tapes were later transcribed. In one case, time constraints made it impossible for an interviewer to visit a service located in a more distant part of the State and the interview was conducted by telephone. An interview protocol was also completed by one of the staff associated with this program. Information contained in the completed interview protocols was coded and the results of this analysis form the basis of the discussion that follows. A copy of the interview schedule is attached (see Appendix B). It should be noted that the percentage results reported in Chapter 6 are based on a percentage of programs within the sample of 27 sites that were included in the review.

Information collected from CWSD files and site visits, and from interviews held with staff associated with the programs included in the survey, is summarised in the next two chapters of the report. Most of this material was obtained from discussions with the staff member who was responsible for the preparation of applications for the CWSD Program, but, where possible, discussions were held with other staff associated with the implementation of the project. In a few cases, discussions were also held with parents.

CHAPTER 4

RESULTS: CWSD RECORDS

Useful information for the review was obtained from two main sources; the files held by the CWSD Program administrative officers and the material, including completed interview schedules, collected during discusssions held with project staff on site visits. In this chapter, material obtained from CWSD Program files is considered. Data collected from site visits and discussions will be reviewed in the following Chapter 5.

From information obtained from summary records which were made available to the research team by CWSD administrative staff, the following results were compiled.

4.1 Distribution of funds by category of expenditure

According to the CWSD Program guidelines, funds could be requested to cover the cost of salaries for teachers and other specialist staff, professional development, consultancy, travel, curriculum development, equipment and program evaluation (see Table 2.3). However, grants usually covered only a few of these items. For example, most projects included in the review were granted funds to cover the cost of all or part of a teacher's salary. These funds represented around 80% of all expenditure on these sites. In addition, 14 projects received full or partial funding for an aide position (18% of all expenditure). Equipment allowances were made for four projects (0.2%), a transport or travel subsidy was paid to four projects (0.5%) and a sum for administration was also allocated to four projects (1.0%) (See Table 4.1).

It is interesting to consider the data set out in Table 4.1 on the various categories of expenditure for the selected review sites, in comparison with all sites funded in 1981, 1985 and 1989. In 1981, only around 30% of funds were allocated to teaching positions, while 17% were committed to therapists or psychologists and a further 12% to program co-ordinators. By 1985, the teacher component of salary allocations had risen to 57%, funds for aides to almost 20%, while therapists/ psychologists had fallen to 13%. However, by 1989, around 80% of funds were allocated to teaching positions and the remaining salary items limited to aide positions. Similar changes in emphasis are evident in non-salary items.

TABLE 4.1 DISTRIBUTION OF CWSD FUNDS BY CATEGORY OF EXPENDITURE, 1981, 1985, 1989

Funding Category	1981(1)	1985(1)	1989 (all projects)	1989 (sample projects)
Salary	%	%	%	%
Teacher	29.2	56.7	79.3	80.3
Aide/clerical	7.6	19.5	18.2	18.0
Other: coordinators	12.2	-	-	-
therapists/ psychol.	17.2	13.0	-	-
TOTAL SALARIES	66.2	89.2	97.5	98.3
Non-salary				
Admin/clerical	3.4	1.6	0.9	1.0
Equipment	13.6	4.5	0.3	0.2
Transport	11.7	4.8	1.3	0.5
Other: minor works	5.1	-	-	-
TOTAL Non-salaries	33.8	10.8	2.5	1.7

(1) Source: Ferguson & Ward, 1986, p.21

Equipment expenditure reduced from 14% of allocated funds to 0.3%, and transport costs from 12% to around 1.0%. These changes probably reflect, in part, differences in the category of projects funded over the time period (See Table 2.1).

It is interesting to note that some of the funding categories listed in guidelines for the Program do not appear to have been used in the funds allocated to the sites selected for this review. For example, no grants were made, at the site level, for specialist staff other than teachers, professional development of parents and staff, consultancy and advisory services, curriculum development or monitoring and evaluation of programs.

TABLE 4.2 DISTRIBUTION OF CWSD FUNDS BY CATEGORY OF EXPENDITURE 1989: (NON-SAMPLE AND SAMPLE PROJECTS)

	Number of Projects		
Expenditure	Non sample	Sample	Total
Teacher only	8	10	18
Teacher plus aide	3	7	10
plus equip/travel	1	1	2
plus equip/admin	-	2	2
plus travel/admin	1	1	2
plus equip/travel/ admin	2	1	3
TOTAL: Teacher only	8	10	18
Teacher plus aide plus non-salary	7	12	19
Aide only	2	2	4
Aide plus travel	1	1	2
plus admin/travel	2	-	2
TOTAL: Aide only	2	2	4
Aide + non salary	3	1	4

From data set out in Table 4.2, some interesting trends emerge about the pattern of distribution of grants in terms of combinations of expenditure for teacher and aide positions, and for non-salary items. Overall, 18 projects were funded for teacher salaries only and a further 10 for teacher and aide positions. An additional nine projects received an allowance for both types of salary positions and some non-salary costs. The three projects that received an allowance in each of the five categories of funding were all small rural projects catering for groups of children numbering less than 10.

However, of more interest are the eight projects that were funded only for an aide position, or for an aide plus non-salary items. Only three of these projects were included in the review sample, primarily because the remaining five projects were located at some distance from Sydney or catered for students of school age. Apart from one project which provided an aide to assist a student with physical disabilities enrolled in the Correspondence School, the other positions appear to have been operated in association with a hospital and/or therapy services and the local developmental disabilities team. Since one of the main areas of the CWSD Program is to provide an educational component to a range of, mainly therapy, services which have traditionally been provided for children with severe disabilities, care needs to be taken to ensure that all projects supported by CWSD grants include a strong educational component, provided by a teacher who has appropriate training and experience who can work successfully within the context of a multi- or transdisciplinary team.

4.2 Number of Children participating in projects

The number of children anticipated to participate in the selected sample projects totalled 436. This included one large therapy-based service which anticipated that a total of 81 children would be served during 1989. Excluding this latter group, because of the large number of children involved, the average number of children expected to participate in each of the other projects was approximately 14 (range 4-31). Among this group, 57 children were located in residential insitutions, the majority being in long term care.

4.3 Funding allocation per child

Taking into account the number of children anticipated to be associated with each project, together with the total funds allocated to that project, a rough per capita rate can be estimated. According to this calculation, the level of funding provided per child ranged from just under $600 to over $4,000 (see Table 5.3). The largest percentage of projects in both the selected sample sites and in all programs provided for children in the 0-6 age range were funded at a per capita level of between $1,500 and $1,900 (39% and 36% respectively). Only small numbers of children were involved in projects that were funded at per capita rates of $2,400 or more: these tended to be resident in long term care settings.

TABLE 4.3 DISTRIBUTION OF CWSD FUNDS ON A PER CAPITA BASIS: ALL PROJECTS (0-6 YEARS) AND SELECTED REVIEW PROJECTS (PERCENTAGES)

Funding Category	All Projects (0-6 years) %	Sample Projects %
Under $1000	15	15
$1000-$1400	19	19
$1500-$1900	36	39
$2000-$2400	19	19
$2500-$2900	2	-
$3000-$3400	2	-
over $3,500	7	8

4.4 Administering Authority

In terms of administering authority for the CWSD grants, the projects surveyed fell into nine main categories, as set out in Table 4.4. Most were parent or community-based groups (37%) or were associated with community preschools (11%). A further 18% were administered by services associated with the Department of Health.

TABLE 4.4 DISTRIBUTION OF PROJECTS BY ADMINISTERING AUTHORITY ALL PROJECTS (0-6 YEARS) AND SAMPLE PROJECTS (PERCENTAGES)

Administering Authority	All Projects (0-6 years) %	Sample Projects %
Charity	10	15
Parent or community group	31	37
Community preschool	12	11
Long day centre	7	7
Religious organisation	2	4
Private hospital/Nursing home	7	4
Department of Health	21	18
Department of Education	5	4
Tertiary Institution	5	-

4.5 Pattern of Service Delivery

Within the projects included in the review, various patterns of service delivery were reported, in terms of the actual location of the program. Nineteen (69%) were described as centre-based, and eleven (38%) reported that their program included a home-based component. However, only one program was solely home-based and most of the others only provided occasional home visits as needed. A few programs operating in more distant rural areas did provide home visits for some families living in isolated areas. Six programs (23%) provided a service within a preschool and a further three reported that part of their service involved support of integration into local preschools. Three programs operated in the context of long day care and two were in child care centres. Three programs were located in long term residential care settings though, in two of these settings, children in respite or short term care also took part in programs. One rural program worked with a child in a special school. One large agency provided services in a number of multidisciplinary clinics. Six projects operated in more than one location; of these, five were rural programs which operated a service in more than one town. Most of the rural-based projects reported that families travelled from surrounding areas to attend the program.

Fifteen of the programs operated in only one service mode; this varied from centre-based programs to those that operated solely in a clinic or in the child's home. One rural program operated in two country towns, with services provided in four different types of location (centre, home, preschool and special school). Overall, five programs operated in two different types of location, four in three different types and two operated in a combination of four distinct settings. Clearly, the pattern of service delivery represented in the programs funded within the CWSD Program varied widely, reflecting the differing needs of the communities in which they were located, and the type of service that had evolved.

The role of the teachers and other staff funded by the CWSD Program also varied, reflecting the mode of operation of the programs. For example, duties included organising and implementing programs designed for individual children in one-to-one settings, operating play groups, advising preschool teachers involved in the integration of children with special needs, devising and implementing programs for children with severe behaviour problems in the home situation, counselling and supporting parents and other family members, liaising with other professionals, working cooperatively within a multidisciplinary team, in-servicing teachers and other staff working with special needs groups and so on. Some teachers worked as part of large teams and others worked in extreme isolation, sometimes travelling much of the time in a van. All of these situations are represented in the programs surveyed for this study. A statement of duties and responsibilities of staff that was collected during the review from one rural early intervention program is appended (see Appendix C).

COMMENT

Overall, on the basis of information derived from CWSD files, it may be concluded that almost all of the services included in the review were early intervention programs or early educational programs, in many cases delivered in association with other therapy services. Almost all of the children involved lived at home with their families: around 12% were in long term residential or respite care. Most programs were administered by parent or community-based groups and were located in premises identified as early intervention centres, but some operated in more than one setting and some teachers provided an itinerant service. More than 20% of the projects were located in organisations administered by government departments, mainly health.

CHAPTER 5

RESULTS: INTERVIEWS AND SITE VISITS

Information collected from discussions with staff and others during site visits to CWSD-funded programs is summarised below. Initially, background information about the 27 programs included in the review is presented. Material related to the operation of the program is then examined in terms of the assessment procedures and the curriculum on which teaching is based. A number of specific issues are examined, including the place of integration in the program that is offered, sensitivity to different cultural groups in the community, the inter-relationship of the various disciplines associated with the program, relationship between professionals and the parents of children receiving services, availability of counselling and support for parents and families and involvement of program staff in advocacy for children with disabilities and their families. Details were also sought during interviews about the operation of the program in terms of its location and physical environment, its administration, staff training and conditions of appointment, and the extent to which the program inter-related with other agencies that provided services for young children with disabilities and their families.

5.1. Background Information

All of the services included in the survey provided programs to children under school age who had severe disabilities. Some of the programs funded by the CWSD grant represented the entire service offered by that organisation, but, in the majority of cases, the CWSD project was part of a wider service. For example, the six programs visited in the Western region of the State were all primarily funded by the CWSD Program. These programs offered a variety of services, largely centre-based and each staffed by an early childhood educator and an aide. Some support was usually provided by therapists and others from the Developmental Disability team in the local area. This type of program can be contrasted with the projects operated in three large residential hospitals in the Sydney metropolitan area, where CWSD funds were generally used to fund or partly fund a teaching position and an aide to provide educational programs for children who would otherwise have limited or no access to such services.

5.1.2 Program Aims

As would be expected, in the light of the guidelines of the CWSD Program, the primary objectives of the programs surveyed were all concerned with improving the developmental outcomes and educational progress of children with disabilities who had been identified in the years prior to school entry. Specific aims tended to reflect the precise nature of the service that was being offered. For example, one program operating in an isolated rural area listed the following program objectives.

1. To provide special education to developmentally disabled children.
2. To provide weekly intervention programs incorporating educational and therapy components in the home environment and/or education centre.
3. To prepare developmentally delayed children for preschool.
4. To provide sufficient educational input to the developmentally delayed child and his/her carers in order to maintain the family unit in their home environment.
5. To facilitate the integration of these children into the school and general community.

A similar set of objectives were identified for a long day care program located in the city, but a slightly different order of priority was set:

1. To support families and, in particular, to relieve the mothers.
2. To provide an educational program for children with severe disabilities.
3. To prepare children in a centre-based caring setting for a better education while the child is at school.

A fairly traditional statement of the aims of early intervention was provided by one centre and home-based rural program. The program aimed to assist each child develop to his or her maximum potential in all learning areas:

1. To provide the child's family with assistance and support, with knowledge and teaching techniques to implement home programs.

2. To integrate the child into the community.

These aims were all consistent with the broad objectives of the CWSD Program, as set out in the 1989 Program guidelines. Some further examples of program aims are included in Appendix D.

5.1.3 Definition of "severe disability"

A major question that arose during the first interviews for the study concerned the meaning of the term "severe disability." No clear statement was provided in the Program Guidelines. However, as part of a broader discussion, a few programs provided working definitions of the term 'severely disabled'. For example, one centre reported that its services were only available to children who would not be accepted into child care or preschool without the support of the early intervention teacher. Another centre defined severe disability as 'a severe lag in one or more areas of development'. A program that provided support to preschool and day-care staff relied on assessments from a therapy team to identify children whose disabilities were sufficiently severe in nature to warrant their inclusion in the support program.

Centres that provided services for 3- to 4-year-old children with a variety of levels of disability do not always distinguish children with severe disabilities from other children in the program: "Funds from other sources are integrated with CWSD funding to provide services for these children. Staff therefore work with children from different funding sources." This option was probably realistic for these programs, given the delay between preparation of a funding proposal and implementation of programs in the following year, and the uncertainty that can exist between the actual level of need of particular children who are enrolled in a service at any time. Some respondents also commented that some children who appeared, on entry to the program, to have problems that were severe in nature, subsequently progressed so well that they could only be described as mildly or moderately handicapped, though if the program were no longer provided the level of severity of the disability might regress to the initial level.

5.1.4 Organisation and Operation

The projects surveyed tended to share a number of common characteristics, in terms of their mode of operation and the age and type of disability represented in the children served. For example, most of the approximately 620 children reported to be involved in the programs in 1989 were in the age groups 24-35 months (26%) and 36-47 months (30%). Only 3% of children receiving services were under 6 months of age, while 9% were over 5 years (see Table 5.1).

TABLE 5.1 DISTRIBUTION OF CHILDREN IDENTIFIED IN INTERVIEWS AT SAMPLE SITES BY AGE (PERCENTAGES)

Age (Months)	Percentage
Under 6	2.7
6 - 11	3.1
12 - 23	15.5
24 - 35	26.4
36 - 47	29.6
48 - 60	14.0
over 60	8.7

NOTE: Figures apply to 550 children for whom age was stated. A further 70 children were identified but no age range given. One centre reported no details of number or age of children enrolled.

As was reported earlier from analysis of CWSD files, interview data showed that most of the programs were centre-based (73%), though a small number (23%) operated in a combined centre- and home-based mode; these were primarily located in country areas. A typical list of services provided by these later programs included:

- "a special program for your child based on a careful assessment of your child's needs
- Small group play sessions
- Home visits
- Practical and emotional support for the parent/carers
- Videos, reference books and educational toys for loan
- Guest speakers when appropriate"

The policy statement of another program located in a rural area stated:

> "We offer a home-and/or centre-based service to meet the particular needs of families. Some families are unable to attend the Centre because of lack of transport or geographical isolation."

The one program which offered only a home-based service described its operation as follows:

> "This is an early intervention program which takes place in the child's own home. The Home-Based Early Intervention Service offers a program to families of children who have been diagnosed as "autistic" or as having "autistic tendencies." It is also suitable for children with severe behaviour problems, with language delay or disorder."

The choice of a home-based model for the service provided by this organisation reflected the severity of the behavioural problems present in the children served and the need for intervention within each child's natural setting.

5.1.5 Category of disability served

The primary disabilities reported among the children were those classified as physical (165 children), multiple (146 children) and intellectual but not including Down Syndrome (116 children) (see Table 5.2). Other categories of disability were much less frequently cited; for example, Down Syndrome (45 children), language disability (39 children) and behaviour problems (37 children). Only 19 children were listed as having primarily a visual problem and 13 were primarily hearing impaired. However, not all centres provided information about the children participating in programs in 1989 and some indicated that the children had more than one primary disability.

TABLE 5.2 DISTRIBUTION OF CHILDREN IDENTIFIED DURING INTERVIEWS AT SAMPLE SITES BY TYPE OF DISABILITY

Type of Disability	No. of Children
Intellectual: Down Syndrome	45
Non Down Syndrome	116
Physical	165
Hearing	13
Vision	19
Language	39
Behaviour	37
Multiple	146
Other	11

NOTE: Not all centres provided information for this question and some included children in more than one category.

Three programs reported that they worked only with children whose disabilities were severe in nature. One of these was a large retardation hospital, another operated as a long day care program for children with severe disabilities and the third provided an itinerant support service to assist preschool and long day care staff working in a number of different locations. One early intervention program provided no information about the level of severity of the children's disabilities, commenting that the staff were unwilling to categorise the children in this way and did not see the appropriateness of such information to their program. Thirteen of the services indicated that they did not exclude any categories of disability. However, some exclusions were noted. For example, not unexpectedly, only children with cerebral palsy were accepted into the programs operated by a therapy-based program and the program for children with severe disturbances did not accept children with physical impairments.

The long day care centre that accepted only children with severe disabilities in its program also noted that children whose problems were mild or moderate in nature were not accepted; nor were children who were primarily behaviourally disturbed. This program tried to take the children who were considered to be 'hard to place' and whose potential was unknown; for example, less that half of the children were mobile, three were tube-fed and two had severe cerebral palsy but may not have been intellectually impaired. This program did not accept children with Down Syndrome on the basis that the disabilities of these children were usually moderate, rather than severe, in nature. Several programs reported that they usually referred children with primarily behavioural or emotional difficulties on to other agencies, preferring to work with children who had an intellectual disability. One rural program noted that a child with a severe visual problem was referred on to the Royal Blind Society and several programs noted that they would not accept children who were mildly disabled or those whose difficulties were solely in the area of language delay. Those programs that did include children with disabilities that were mild in nature usually received funding for this group from a source other than the CWSD Program, such as the Early Special Education Program.

5.1.6 Age of children

As noted earlier, most of the children associated with CWSD programs were aged between 24 and 48 months. Some programs actually restricted their intake to children in this age range. For example, the long day care centres in the Sydney area restricted their services to children in the age range 18-48 months. One such centre reported that "severely handicapped children under 18 months would not be accepted because there needed to be time for bonding to occur and for the mothers to explore all the other services that were available; particularly the various therapy services that might be appropriate for the particular child. Many programs aimed to prepare the children for integration into a regular preschool, so it was anticipated that by 48 months, the children would be ready to move on to an integrated setting.

Services providing programs for children over 5 years tended to be associated with residential care settings, with children in long term or, in some cases, respite care. In relation to the placement of children with severe disabilities living at home, it was reported during an interview at one Sydney-based program, that these children would be expected to begin attending the nearest School for Specific Purposes once they turned 4 years of age and so would not be permitted to continue to attend the CWSD-funded program.

5.1.7 Waiting Lists

There was some variation in the average time that children wait to join a program. Seventeen of the programs surveyed did not have a waiting list, though several indicated that demand for the service was increasing and they anticipated that a waiting list would have to be formed. One program which was wholly funded by CWSD did not have a waiting list, largely because there had been no appointment made to the coordinator's position until half way through the year, owing to the lateness in payment of funds. Another service reported that children were placed on a minimal service until a full place became available in the program. There was also, in some cases, a period of waiting while parents made the decision to accept a placement in a program.

5.1.8 Referral and Selection of Children

Most programs reported a number of different sources for referral of children to the program. The majority (73%) reported that paediatricians, the local G.P. or other medical practitioners recommended children for assistance. More than half (58%) noted that Baby Health Centre sisters directed children to the program, together with therapists and parents who self-referred (both around 54%). Some families were sent by preschool staff (27%) and by Developmental Disability or F.A.C.S. Officers. There was also some referral across agencies associated with the CWSD Program; a long day care program received referrals from the Spastic Centre, the Autistic Centre, Grosvenor Hospital and other similar large organisations. Two small early intervention programs received all their children via larger umbrella organisations.

Children were mainly accepted into programs on the basis of assessment information; 61% of responses indicated that a therapist, a member of the Developmental Disability team or similar professional provided information about the child, based on an assessment. One rural program described a weekly meeting with all members of staff present, together with representatives of the Developmental Disability team and Child and Family Health, occasionally the local G.P. or paediatrician and speech pathologist, all of whom referred children they had assisted to the program. A S.U.P.S. worker also joined this meeting from time to time. Some programs reported that they accepted all referrals, but these tended to offer a variety of programs to children with a range of levels of disability.

5.2 ASSESSMENT

As noted earlier, assessment and curriculum are critical components of any teaching program, and are particularly important in early intervention. The information collected in this part of the study is therefore of considerable interest, since it concerns an aspect of the operation of the programs that is crucial for the progress of the children concerned.

5.2.1 Initial assessment procedures

In terms of initial assessment procedures, following entry to the program, a variety of methods of data collection were reported. For example, some programs used informal observation and check-lists, but a number of published programs were also mentioned, including the Developmental Skills Inventory (Pieterse, Cairns & Treloar, 1986; 46%), Hawaii Early Learning Program (Furund et al, 1979; 11%), the Learning Accomplishment Profile (Sanford,1974, 8%), Irrabeena Scale and a range of other resources. Background information was usually collected from parents and data obtained from observation of the child during play and in interaction with his or her parents. This process involved more than one session in most programs (78%), with information collected by a team (81%) rather than one person (19%). Where a team contributed to the assessment process, this usually included a teacher (92%), a physiotherapist and/or occupational therapist (both 77%), speech pathologist (38%), paediatrician (23%), psychologist (15%) and social worker (8%). It is not clear if these patterns of involvement reflected the availability of these personnel as much as a planned program of assessment from a multidisciplinary team. However, some programs indicated that the factors that determined which staff contributed to an assessment were usually determined by the child's disability (42%); staff availability was mentioned by only 15% of respondents.

One program located in a non-metropolitan area noted that it was important for all disciplines to see each child because the teacher "feels she does not pick up all the problems; e.g. the physiotherapist may see things that the teacher might miss." In contrast, a city-based program commented that "only a special education teacher was available." This program had close links with large referring agencies that were able to provide support from therapy services, if necessary.

Most assessment took place in the centre (58%), but a number of programs reported that the assessment process was conducted in a variety of settings (38%). Programs that accepted babies reported that they were sometimes assessed initially in the hospital ("this is more often family focussed rather than focussed on the child alone"). Occasionally, a child would be assessed at home "if the family had no transport", noted one respondent from a rural program.

5.2.2 Ongoing assessment: frequency and procedures used

In relation to the frequency of assessment, most centres reported that informal assessments were usually conducted as part of the ongoing program. Six reported that more formal assessment was carried out at six monthly intervals and four programs noted that annual formal reviews were made of children's progress. One rural program reported:

> "Informal assessment - ongoing - as need arises. Formal - DSI at end of each term when parent interviews are held (sample letter for parents about the interview is attached). Parent Interview sheet is completed by staff before the parent interview and parent concerns are noted during the interview."

A variety of different types of information was collected during assessments. For example, a home-based program working with children who had severe behaviour problems reported that individual children's files included referral material, psychological reports, welfare reports, monthly teachers' progress reports on the child and details of contacts made with other agencies. A large therapy-based service reported that information collected on each child included material related to the child's family background, the child's areas of difficulty (physical, sensory etc), current play skills, family's daily and weekly routines, the child's likes and dislikes, toy preferences, daily living skills and parental priorities. A long term care hospital reported that records kept included a short medical history of the child, records of previous therapy, assessment records and program progress reports.

Among the various assessment procedures reported to be used within the programs, observation was one of the most common: 73% reported that some information was collected through observation of the child, primarily in the setting of the centre (62%), but also in a variety of other locations (home, clinic, preschool) (35%).

5.2.3 Parental involvement

Parents were generally not involved in the assessment process, though many of the programs (62%) indicated that parents contributed important information to the assessment process. Not unexpectedly, parents were least likely to be involved when the child was in residential care or in long day or child care. In the latter cases, a communication book was sometimes used to keep parents in touch with the program and with the results of assessment. Some program staff were cautious about the role that parents could play in the assessment process:

> "Parents' reports (verbal) are taken with caution. Depends on stage of acceptance. You may not initially get the full story from parents. They may tell you what they think you want to hear."

However, a more typical comment was provided by a long day care centre outside the metropolitan area:

> "Parents provide information about the child's abilities and performance levels outside the Centre."

An interesting comment was made by a respondant from a program located in a rural area. She noted that informal observation would be done at the preschool, if this was requested by the preschool teacher. However, no assessments were carried out in children's homes. Apparently, in that area, there was considerable resistance by families to home visits. Parents were anxious about a member of the Early Intervention Program visiting the home, particularly when it involved a member of the staff who belonged to F.A.C.S. These officers often were required to visit homes in relation to custody and other similar cases and this association created anxiety about any home visits from program staff.

5.3 CURRICULUM

Questions asked about curriculum in the interview schedule covered issues related to assessment for programming purposes, identification of teaching objectives for individual children, form of curriculum used, resources available, teaching procedures, records and parental involvement in the teaching program.

5.3.1 Selecting objectives

As might be expected from information presented in the previous section, almost all teaching programs were based on assessment data, though other sources of information were also used in program development, including, in some projects, consultation with parents. Several programs also used assessment information as a basis for ongoing program evaluation. Individual teaching objectives and, in some cases, IEP's were identified for each child in all of the programs, primarily from results of assessments (often observational) by teachers, therapists and, occasionally, parents:

> "Objectives (on a weekly basis) are set by teacher and occupational therapist. Aide will use these to devise appropriate programs when supporting child on home visit, at preschool or small groups." These objectives are identified "from assessments and follow-up by teacher or O.T. Informally, parents may indicate concerns."
>
> "2 or 3" specific teaching objectives are identified "in each developmental area. However, if necessary, we will work extensively in one area." Objectives are identified "through assessment by members of team. Primary interventionist may be.
>
> - first person contacted.
> - person who has a comfortable relationship with parent.
> - person who has time.
> - person with experience in area of disability.
>
> IEP's are developed by "team and parents who are considered 'part of the team"; parents are involved - through parents interviews."

The areas of the curriculum covered by teaching objectives varied: most projects indicated all developmental areas were included in teaching programs, while others focused on "areas of greatest need" or areas of greatest concern to parents or staff (e.g. dribbling).

5.3.2 Form of curriculum

A variety of different curricula were reported to be used ranging from the D.S.I. (Pieterse et al., 1986; 7 projects), H.E.L.P. (Furuno et al., 1979; 4 programs), the NSW Dept of Education Program for students with Severe Disabilities (3 projects) to curriculum developed by project staff (five centres). One member of the research team commented, in relation to the curriculum used in a rural early intervention project she had visited:

> "Note, the staff here are all very experienced and seem to use bits of everything, but don't keep good records. In my opinion they've got careless about the use of curricula and just use their own ideas."

5.3.3 Curriculum resources

Two centres reported that toys were the most important resource available to them and two reported using material from toy libraries. Some projects had access to fairly extensive resource materials. For example, in one large therapy centre had access to a wide range of resources ("We have a good budget"). However, other smaller centres appeared to have more limited access to such materials:

> Curricula resources available to the program include "parents' experiences; books on early development."

Three centres reported using materials provided through the NSW Department of Education Student Support Services Resource Unit; specific reference was made to videos, library books and mobility equipment. Other smaller centres appeared to have fairly limited access to resource materials.

5.3.4 Type of Program

The types of programs offered varied widely, but most projects included both individual, one-to-one teaching situations as well as small group activities, sometimes designed to prepare the children "for coping in the next environment." For example, a metropolitan long-term care unit reported that children involved in the project took part in two group sessions and one individual session each week. In addition, they had programs provided by both occupational and physiotherapists. A rural early intervention project reported that the types of programs provided included:

> "Individual, medium group (4-8 children) small group (2-3 children) centre-and home-based."

5.3.5 Purpose of programs

The primary purpose of these various curriculum activities varied across the different projects. For example, three residential care centres reported that the activities provided within the CWSD project were designed to improve levels of independence and quality of life:

> "give kids a sense of pleasure, movement, other related activities."
>
> "get level of functioning as close as possible to independence."
>
> "child centred - to encourage independence."
>
> "try to improve independence in basic skills, a few can progress. Others are not likely to achieve independence but can improve the quality of life. Their choice is very primitive."

Responses from community-based early intervention projects referred more frequently to preschool preparation and integration, as well as independence, as the major focus of what they were trying to achieve with their teaching activities:

> "Independence, self-esteem, functional living, least restrictive next environment."
>
> "important for children to have play skills, communication skills, social skills if they are going to integrate into preschool and school."
>
> "Individual: Specific skills for cognitive language, self-help, depending on child's objectives. Group: Social skills, language, cognitive and self-help within an integrated setting.
>
> "to develop independence; to develop a functional means of communication; to develop a range of basic skills."
>
> "acceptance and ability to operate in the community, functional independence as much as possible - integration e.g. "group" skills/acceptance such as sitting and waiting at doctor's surgery; requesting food or drink; stopping unacceptable behaviours."

Most of the projects reported that they tried to integrate activities from different developmental skill areas in their programs, such as encouraging children to use signing to make socially acceptable requests, sitting independently at meal time with other children, standing during a game (with help of physio) or holding a paint brush to paint (grasping).

5.3.6 Program implementation

Teaching took place "everywhere - centre, home, preschool, community." Most respondents appeared to recognise the value of implementing curriculum goals in a variety of settings. Some reported that teaching primarily took place within a classroom or surrounding areas, though most also mentioned other "outside" locations:

> "Classroom, for groups. Swimming sessions. Lunch out sometimes. One excursion day each week and a caravan holiday each term." (a residential care unit).
>
> "Here in the hall. Sometimes in the park." (a rural early intervention project).
>
> "Within the Centre a) during normal activities, and b) in withdrawal situations in a quiet but familiar part of the Centre." (child care centre).

One rural project answered very simply that teaching took place "here, on the floor." Most programs also took advantage of these various teaching situations to allow children to practise new skills in different situations. Many also reported that staff liaised with parents, preschool teachers or play group leaders:

> "Yes, children are encouraged to practise new skills at home and at preschool. We have contact with the preschool teacher - tell her what our current goals are and send her a copy of the D.S.I. assessment."
>
> "Yes, home - group - playgroup - preschool. e.g. use a cup for snack at home and at snack time at preschool."

However some projects did not have time to set up links with other centres also working with a child:

> "Yes, children encouraged to practise new skill at home. But we don't have time to contact the preschool." (rural intervention project).

One project working with children who had difficult behaviour reported :

> "Mothers are encouraged to act as co-therapists but there is no pressure on them. The teacher works with the child at home and inadvertently, mothers begin to learn what to do."

5.3.7 Program records

In relation to the records of teaching programs, all projects reported that records of assessments were kept. Almost all projects (88%) kept details of long term goals and progress reports (85%). Records of current daily or weekly goals were maintained by 73% of projects. Where regular team meetings were held, minutes of these discussions were also kept.

5.3.8 Parental involvement

The majority of projects (85%) involved parents in the identification of teaching objectives though some qualified the contribution made by parents to this aspect of programming:

> "Some parents are involved" (a residential care unit)

> "Yes parents are involved as far as possible" (rural early intervention project).

> "Yes, 50%, through their interest and understanding. Others are not interested and expect the teacher to do it all." (rural early intervention project).

One rural project clearly valued the contribution made by parents to program planning:

> "Yes, parents point out needs. They have valuable ideas and voice their preferences."

Similarly, most projects (85%) reported that parents were involved in the teaching process, both at home (65%) and in the centre (50%).

> "Parents carry out the program at home, using materials which are available in the home. (Teachers check what is available in the home environment and plan around this)." (rural intervention project).

Some projects required parents to stay and help in the program.

> "Parents are rostered in the play group, though not each session."

> "Parents have to stay and must help their child in craft activities. They may join in the play groups and language group and are always involved in individual teaching." (rural intervention projects)

In contrast, the projects based in child care centres, generally did not expect parents to take part in teaching activities.

> "Parents are not directly involved; but they are informed of procedures being used, involved in follow-up at home, involved in problem solving e.g. behaviour management etc."

A project associated with a large therapy service noted that their programs were home-based, in that parents were intimately involved in carrying out suggested activities at home. In contrast, where children were in residential care, parents were rarely involved. For example, one residential unit stated that "the babies are too sick, though parents used to be involved" and another commented that parents were "informed about programs in half yearly reports." A similar facility that included children from both the community and the residential care setting noted that:

> "Parents are not really involved, unless the task needs to be done at home. Therapists do home visits and involve parents and they are kept informed through telephone calls and a daily communication book (Community Children)."

5.3.9 Unstructured play

The centres varied in their views on the place of unstructured play in their programs. Most respondants (73%) stated that they encouraged play activities of this type. However five centres stated that children with disabillities generally needed specific objectives and support rather than "free play to participate in such activities." One centre noted:

> "In some students unstructured play sessions are important because they:

> a) give the teacher insight regarding the development of imaginary play.
>
> b) provide opportunities for spontaneous interaction with another child, as well as for incidental learning.
>
> c) enable the teacher to observe if the skills taught during the "structural play sessions" are being generalised. However, some children are not ready for unstructured play session.

This last comment was repeated in the reply from an early intervention program in a city-based centre:

> "Unstructured play has been found to have very limited value until the child has some play skills. We attempt to teach such skills which can be used later in an unstructured setting."

Other centres commented that play sessions were planned and involved setting up structured alternatives in such a way that they appeared unstructured, but still taught particular skills.

5.4 OTHER PROGRAM ISSUES

5.4.1 Integration

All of the centres stated that their programs included specific goals and activities designed to prepare children for integration. Emphasis was usually placed on the development of communication, self-care and socialisation skills, together with encouragement of acceptable behaviour in preparation for preschool or other integrated settings.

In 81% of the centres, attendance at regular pre-school, day care centres or playgroups was either encouraged or arranged for at least some of the children. In addition, more than half (55%) of the centres arranged for some form of reverse integration, by inviting siblings or other non-handicapped children to attend some sessions. Some use was made of community facilities to provide contact with other children by a number of programs (67%). For example, some arranged for program children to attend a community playgroup, others took them swimming at the local pool. However, only 27% of respondants reported arranging excursions to use community resources on a regular basis. This may be more important for children living in a residential situation than for children living at home.

Integration and normalisation were among the main objectives cited by all programs, and all claimed that every endeavour was made to prepare the children so that they would be "as independent as possible and a contributing and accepted, member of the community." This objective was often stated in the program's constitution (15%) or on some other document produced by project staff or committee (65%). Clearly, integration is seen as a basic principle underlying all the projects included in this study.

5.4.2 Cultural sensitivity

Only about half of the centres reported having children from diverse ethnic backgrounds enrolled in their programs. These tended to be located in inner-city areas that had a high percentage of families from migrant backgrounds:

> "More than 60% of our families do not have English as their first language. This does not really present a problem; most teaching is modelled. We use interpreters if necessary."

One program reported that its booklets for parents had been translated into 15 different languages. Staff at this program also commented that the cultural expectations of some families from non-English speaking backgrounds posed an enormous problem for them. They felt that all the programs operated by that service could improve their relationships with families from the various ethnic groups.

Some programs reported that the religious festivals and special diets of some of their families were respected, as were different customs, clothing and behaviours. Only half of the centres with high ethnic enrolments found it necessary to use translators, because these families often had one member who spoke English. However, when translators were required, they were generally available.

Some programs located in rural areas had families from Aboriginal backgrounds. Relevant comments about the provision made to help these groups included:

> "This program has some Aboriginal children and a special Aboriginal aide to work with those families."
>
> "We have some Aboriginal children and treat them the same as other children. Three children from the Special Aboriginal Long Day Care Centre come here, two are in the CWSD program."
>
> "Special care with one Aboriginal child (Down Syndrome). E.I.teacher visited the child in the Aboriginal Pre-school Centre and then arranged for him to go to the special school at age 4, as this way he gets taxi pick-up and regular attendance."

In general, the programs that provided services to children from Aboriginal backgrounds had few or no families from Non-English speaking backgrounds.

5.4.3 Transdisciplinary approaches

Professional responsibility for individual families was, in general, assumed by the teacher, or program director, often in asssociation with the referring agency. Decisions about such responsibilities were generally made at team meetings or case conferences, In 26% of centres, it was noted that allocation of responsibility for individual children and families tended to vary throughout the enrolment period, depending on specific needs of the family or on the decisions made by project staff at regular meetings. In 15% of projects, responsibility was governed solely by the child' needs.

Access to professional assistance was readily available to most of the centres (88%). However the range and frequency of contact with the services varied considerably. Those centres situated in larger towns or cities were generally able to access all therapies, medical specialists, Developmental Disability teams, social workers and so on.

> "Yes. A close liaison with the childrens' therapists is maintained, and referrals for assistance are often made. Several therapists like to come and see their clients at

> the Centre once a month or so, especially when making assessments, as they find the child performs better in the familiar surroundings. We often seek their advice." (child care centre and preschool in outer metropolitan area)

However, a few of the more isolated centres had some difficulty in arranging appointments with therapists and other support services. Often the child and family had to travel to the professionals, or wait for one of the infrequent visits made to the centre. One program reported their contacts with the various professionals who assisted their families were not always satisfactory. For example, although therapists frequently saw and treated some of the children, there was little or no cooperation or communication with the teacher about the program that was being provided at the Centre. Better communication was needed between the various professionals involved with the children and staff working in the early intervention program.

> "A major problem is the relationship of the teacher to the therapists whom the D.D. Team has allocated to her. They attend at times when she is not available - no counselling or sharing assessment or training, in contrast to the community hospital Speech Therapist who comes occasionally to her play group and gives her ideas." (Comment from a member of the research team)

One respondent from a city long day care centre noted that many of the children who were enrolled in the program already had links with professionals, often through their referring agency. These children usually continued to receive support from these various sources. In most of the centre surveyed, the professional services that supported program staff were community-funded. They were not funded through the CWSD Program. These comments suggest that therapy and other support services are generally not delivered in the context of a multi- or transdisciplinary service model.

5.4.4 Program Evaluation

A majority (78%) of the centres reported that they had been evaluated either formally (35%), informally (38%) or both (8%). Most evaluations were carried out by a combination of program co-ordinators, teachers and other members of the staff, together with parents and the committee (if any). About 27% of respondents stated that program evaluations were done specifically for funding purposes. Of the external evaluations that had been carried out, some were associated with research being conducted by tertiary institutions and others were associated with representatives of generic services (e.g. Developmental Disability Teams, FACS officers or School Counsellors).

Undoubtedly, the program evaluation component associated with CWSD funding applications was a major impetus for at least some internal reflection by staff about the operation of their program over the previous 12 months. Smaller, community-based programs, where staff were actively involved in decision-making about the operation of the service and in the preparation of submissions for funding, were most likely to be involved in such an evaluation process. For example:

- "We have an evaluation committee which evaluates us every 6 months. The committee includes the School Counsellor, a teacher of the visually impaired and a mother (not in the program)."
- "Team meetings provide an opportunity for reflection (7 staff members attend team meetings)."

Larger service-type agencies were less likely to have ongoing or regular evaluation: for example, one teacher in a residential care unit indicated that no evaluation was carried out, though practices were reviewed at approximately 12-monthly intervals.

5.5 PARENTAL-PROFESSIONAL RELATIONSHIPS

In 24 of the 27 centres, the fostering of the parent/professional relationship was deemed very important, and the parents were regarded as integral members of the team working for the child. Because of the heavy demands on their time, many respondents indicated that the involvement of parents was invaluable.

Most centres indicated that parents had free access to files held on their children. Copies of all assessments and reports were usually made available to parents (eg "parents receive a carbon copy of all documentation"). One centre reported that parents were actively encouraged to request copies of all reports and to keep the documents in a folder. Two centres had reservations about giving parents access to letters from doctors or medical reports: "they must have assistance with medical files." One recently appointed staff member commented that she "spent a day with the Committee and parents but they had no access to individual children's records and had not requested this so far."

5.5.1 Home visits

The centres were about equally divided in relation to the provision of some form of program in childrens' homes; 14 projects included a home-based component while 13 did not. The services provided in homes varied from regular visits (21%) which were intended to monitor a child's progress, review teaching strategies and program objectives; to occasional visits (29%) to obtain feedback from parents or to provide family support, or address parental concerns. More practical reasons for home visits included organisation of equipment or modification of some part of the house, to more adequately cater for a particular need. In some instances, home visits were provided only in times of severe illness or emergency, or when distance was a problem. In other cases, when time permitted, the teacher and/or therapist visited children's homes to establish contact with fathers and siblings in the home environment. Lack of funding and time was the main reason reported for the non-provision of home visits, although one centre reported that there was some distrust of home visits from single parents, and embarrassment for some families.

> "Home visits proved to be impossible - too many children and the problem of low socio-economic parents not

> comfortable with it. This is due to the fact that teachers must make reports to FACS regarding a number of children. Although these reports are shown to parents, there is some disquiet. Also, single parents are often distrustful of some visits."

The teacher at one rural centre commented that home visits were made as part of transport arrangements to bring children to the program:

> "There is no time for home visits. I have made an occasional visit to homes with no transport. Actually, I pick up children in my own car and bring them to the Centre - the Committee pays me for transporting them"

5.5.2.Parent Counselling/Support

Most of the centres (73%) recognised the need to provide some form of family counselling, albeit on an informal basis. Since relationships with parents were generally good, problems about a child's program were often able to be resolved through informal chats with parents by the teacher or a visiting professional. If it was felt to be necessary, almost all centres (96%) were prepared to refer the family to an appropriate professional service. In several cases, the agency that initially referred the family to the program was contacted and asked to assume responsibility for obtaining counselling or other support for the family. In other centres, staff had contact with local clinics, health centres or hospitals where social workers, psychologists and psychiatrists were available to provide the necessary asssistance. Social workers were regarded as the primary source of family counselling by over 40% of the centres.

5.5.3 Parent support groups

Most of the centres recognised that parents of children with disabilities could be helped through contact with other families who had experienced problems similar to their own. Parent-to-parent support groups operated in more than half (58%) of the centres surveyed, and most programs assumed responsibility for informing parents about the existence and functions of these organisations, usually by means of regular newsletters. These support groups ranged from parent associations organised by outside agencies in the local area, such as the Parent Support Group for Children with Disabilities and specific disability support groups such as the Down Syndrome Association, through to regular formal meetings of parents at the centre and monthly morning teas for mothers. Of the 10 programs that had no formal support group currently operating, eight indicated that there was some informal contact among the parents that had been initiated by project staff. In addition, half of these centres noted that the playgroup which operated within the centre also functioned as a support group for parents.

Most of the centres (89%) arranged for parents to make informal contact with other parents associated with the program. For example, seven (26%) reported that they encouraged parents to get together, usually after play group, or through monthly meetings. Four centres stated that they actively arranged contact between parents of children with similar disabilities. For the most part, such contact was achieved through predominantly social functions, such as Christmas parties, open days, fund-raising events, or excursions. One centre noted that if parents wanted contact with other parents, they usually managed to organise it themselves.

5.5.4 Parent entitlements

Most (80%) of the centres offered information to parents regarding their entitlement to benefits, allowances and services. Some assisted fully, helping parents to fill in the appropriate forms, arranging visits to a paediatrician or other specialist, following up the referral, if necessary, and directing them to local childrens' services or respite and home care. Others gave informal verbal advice when requested. However, not all respondents indicated that this form of parental support was their responsibility. For example, staff at one program gave advice only when it concerned the centre itself, such as eligibility for fee relief. Respondents from three centres which did not provide this type of advice or assistance stated that, in most cases, parents had already been advised about their entitlements by the referring agency, prior to their enrolment in the program.

5.5.5. Parent training

Very few of the centres reported that they offered regular training courses for parents. Two claimed that they provided courses for parents on a regular basis, while other centres noted that parent training courses were organised from time to time, taking the form of discussion nights or workshops, usually on a one-off basis. One centre stated that, although the staff did not offer courses for parents, they did refer parents to relevant courses in the community. The most frequent topics dealt with in courses organised for parents included behaviour management, child development, early communication and language development, signing, siblings and integration.

In view of the fact that parents of children with severe disabilities are likely to be deeply involved in the provision of appropriate services for their children over a long period of time, either in a direct way or more indirectly, in an advocacy or monitoring role, it can be argued that every effort should be made, at this early stage of the children's development, to provide effective training programs that will give them necessary skills.

5.6 INTERAGENCY COORDINATION

The majority of the centres (73%) worked closely with other agencies in the provision of co-ordinated services for the children. Most of these programs stated that they maintained close links with the referring agencies such as FACS, Royal Blind Society and the Spastic Centre of New South Wales. Staff from these centres regularly participated in interagency meetings. Only 15% of respondents reported that their program played no role in co-ordinating services with other agencies. One program reported that staff participated in case conferences with other agencies, and a few reported that they acted as referring agencies, directing children on to other centres.

5.6.1. Future planning for service development

More than half (63%) of the centres reported that their staff were actively involved in planning the future development of services for young children with disabilities in their community. However, some programs (38%) commented that they were not involved in such planning. Contributions to the planning process included preparation of applications for grants to enable the provision of improved services, lobbying for early intervention classes to be established, evaluation and input to local planning and to the development of a community profile. Some centres helped by collecting statistics about the incidence of disability and others reported that they contributed to local development by providing the community with positive examples of integration and normalisation and the setting up of supported integration programs where there was a need.

5.6.2 Transfer of children and follow-up support

When children moved on from one program to other preschools or to schools, the centres varied greatly as to the amount of assistance that was offered. Some (30%) gave no follow-up support, or limited their involvement to sending a report, telephoning or visiting the next school, or making a recommendation to the referring agency. Five centres (19%) reported that the staff did everything possible to ensure successful transfer, advising the parents about available options, visiting the new school with the parents, sending reports and test results, holding discussions with future staff about the transition, and generally acting as a liaison between the family and the new placement site. The remaining centres reported that (38%) offered some level of support in the movement of children to their next school.

5.6.3 Advocacy

In response to a question about staff assuming an advocacy role for children and families, most respondents indicated that they did not usually take a public position on issues related to the rights of children with disabilities. Only two programs reported that their staff had publicly supported issues such as the integration of children with special needs into day care centres or government funding for their own programs; "we went to Canberra to argue for DEET funding for our Centre." On several occasions, Centre staff had been involved in sending letters to State and Federal politicians and on one occasion, a welfare worker had fought for housing for a family associated with a Centre. One comment suggested that the lack of advocacy on issues related to children's rights was due to "not enough time." Another large program noted:

> "There is a policy against this for individual staff. Media are directed to specific staff on particular issues. We did rally against major health cuts."

One centre suggested that public advocacy was the role of parents. However, most of the centres (89%) supported the philosophy that children with disabilities "had as much right as other kids" to available services and community resources. They generally felt that access to services should be a right, not a privilege, and that more services should be made available to children with special needs and their families.

> "Children with disabilities should have the right to education appropriate to their needs, to be treated with dignity and to develop their full potential."

5.7 STAFF

Most professional staff attached to centres were trained teachers (89%) or therapists (16%). Almost half had taken courses in special education (59%) and two had a Child Care Certificate. Five centres (19%) reported that their aides had received some form of training, usually a Child Care Certificate, but others reported that their aides had received no formal training, but had relevant experience; e.g. several were parents of a child with special needs.

Most centres (85%) advertised for new staff when a vacancy occurred, specifying in the advertisement that some form of training, usually "Early childhood and/or Special education" was either required or desirable. However, not all centres required staff to have special education training and one centre commented that advertising was difficult because "the funding was too small." Inservice training was provided by 70% of centres; this varied from on the job training for new staff, informal training ("some videos and books") to a monthly lecture by therapists, attendance at relevant conferences such as the Early Intervention Conference ("Teacher or OT, not aide") and continuing education courses offered by the Institute of Early Childhood Studies and Special Education staff at Macquarie University. Eight centres (30%) reported that no in-service training was offered to the staff.

In relation to conference attendance over the previous 12 months, staff at more than half of the centres (52%) had attended the Early Intervention Association Annual Conference, while 63% listed other conferences that had been attended. Professional development courses that were mentioned most frequently included:

		No. of Respondents
1	Early Intervention Association Conference:	16
2.	CWSD Sponsored workshops: 1988	7
	CWSD Conference: Dr Phillipa Campbell	4
	Handicapped Persons Department training days	
3.	Early Intervention Conference: Orange	5
	Western District Conference: Bloomfield	
4.	Macquarie University Continuing Education	
	Communication: TELL	4
	Teaching strategies	2
	University of Newcastle	
	Behaviour Management	1
	Language for children with sensory disabilities	1
	Charles Sturt University Special Education Conf.	3
5.	Central Coast Children's Services Conference	3
	Austistic Conference, Lismore	3
6.	NSW Department of Education Conference, Leura	2
	Makaton Signing Conference	1
	TAD Conference	1
	Clumsy Child Conference	1

Several comments were made about the need for information about professional development activities to be made available to staff in CWSD funded programs.

The number of programs that sent one or more representatives to the annual conference of the Early Intervention Association is evidence that staff in these programs are interested in attending conferences and professional development activities that are on topics related to early intervention. The number of references made to conferences and courses organised to serve staff in regional areas (eg Western District and on the Central North Coast) suggests that there is some demand for in-service programs and activities that are provided at a regional, as well as at a State level.

5.7.1 Staff induction procedures

In response to a series of questions about staff training and development, it was found that "in-house" staff training was generally limited. Only three programs (11%) had formal procedures for inducting new staff: just over half (55%) of the respondents indicated that new staff or volunteers "watched other staff or worked alongside for a while." However, a city long day care centre reported that "program goals are stated very clearly so that volunteers can quickly pick up and help" while another long day care centre reported a fairly comprehensive approach to introduce new staff to the program:

> "They meet with the Director and other program staff. Opportunities are given to meet or visit previous holders of the position, see other projects and contact therapists and visit associated agencies."

One respondent from a rural program commented that the induction of new staff and volunteers was "a problem, currently under review." Seven programs (26%) indicated that no arrangements were made to train new staff. This issue could present a major difficulty for small programs with few staff. For example, at the time that the visits to projects were being carried out for this review, two members of the research team talked to a teacher whose position (part-time) was funded through the CWSD program. Her duties involved working in an itinerant mode in several different preschool and long-day care sites. She had not been in the position long and felt isolated and uncertain about what was required of her. However, at the time this report was being prepared, approximately 7-8 months later, her position was advertised in a local newspaper. During discussions for this review, the teacher in this program reported that when she began this job, "the Chairperson of the Management Committee had spent a day familiarising her with the program." In this case, there were no other program staff working with the teacher who could "explain to her what to do" or provide opportunities for her to watch others at work, as was reported by some respondents. This is an area in which some guidelines could be developed to help programs to improve the procedures followed in the introduction of new staff and volunteers to projects.

5.7.2 Management training

Respondents also indicated that management education and training opportunities were fairly limited, though six programs (22%) reported that some staff were "doing a business studies course" or "were currently undertaking a degree in managemen at the University of New England." Most respondents (74%) indicated that no management training was being received.

5.7.3 Career opportunities

Overall, the general view of the respondents in relation to their perception of opportunities for career advancement were gloomy. Only one respondent, from a large city-based therapy service, suggested that the prospects were good. Most other respondents (85%) indicated that there were no opportunities for a career to be built within the program in which he or she currently worked. Two respondents did not reply to the question. Reactions to this item included the following:

> "The only benefit is experience in the field"
>
> "limited opportunities, but support is given to staff involved in training."

5.7.3 Working conditions

A number of problems associated with working conditins were also identified by respondents, though the overall level of satisfaction was around 52%. Areas of difficulty included:

(1) Premises (Mentioned by 26%)

> "The present room, a small conference room, is quite unsuitable. The room has to be prepared prior to the children's arrival and equipment has to be packed away" (city-based early intervention project)

> "The premises are most unsuitable, a draughty, dirty end of a hall, otherwise used by senior citizens etc, with equipment locked in a cupboard. The only advantage is that it adjoins the preschool;" (Comment made by a member of the research team about a rural early intervention project)

> "Physical conditions a problem - old building. NB: current building is part of old school building painted in multi-colours, has large room divided into separate rooms by folding doors etc. Storage seems inadequate. Safety aspects for children are questionable as verandah floor appears worn and could have splinters. Comfortable spaces for children and adults are required, etc., etc. Questionable if building would meet Board of Fire Commission requirements!!!" (rural early intervention program).

This last comment raises some important issues about the premises used by programs that have limited budgets, short-term funding and have management committees that are inexperienced in relation to the basic requirements of programs of this type. Clear guidelines should be provided to ensure that all projects satisfy minimum requirements for child care services. However, some projects had a more positive experience to report about the premises used:

> "Starting off - inadequate premises. But now we are in the preschool and it's good. And we are getting an office built." (rural early intervention project)

> "Physical aspects improved considerably with relocation to new premises, September 1989."

(2) Time (19%)

Some respondents felt the demands of their job were more than the time allowed.

> "ten hours per week does not allow time for extra work such as submissions, evaluations, staff meetings, courses etc."

> "Not 9-5 can be a problem.. We get phone calls after hours in the holidays."

> "Need more time to do the job. Use lunch time for meetings, home visits undertaken out of hours." (rural early intevention program)

One respondent who worked in an itinerant mode in preschools and long day care felt there was a conflict between the hours expected to be worked by a teacher and the hours that child care centres operated: "they advertised for a teacher but wanted child care hours."

(3) Finance (15%)

Comments here related primarily to lack of funds for equipment:

> "Not enough funding to have appropriate equipment to use in programs" (rural early intervention program)

> "Space inadequate, equipment poor" (city residential care project)

Other comments were concerned with:

> "problem getting other therapists to co-operate on a regular basis"

> "Too much administrative work"

Not all comments were negative. For example, the respondent from a large metropolitan hospital for children with severe disabilities commented that working conditions were "very satisfactory" and the response from a city-based therapy service was that "working conditions must be good." A long day care centre reported that conditions were "OK though funds to repair the cottage have to come from the main organisation."

Athough most respondents (69%) felt that their salaries and conditions were comparable with those offered in other services, 38% complained that there was no special education allowance or component for administrative responsibility. Several directors stated that their salary included the regular Director's allowance but no extra allowance for working with disabled children. Although the salaries were based on I.T.A. rates, it was felt that those working with severely disabled children had a much heavier work load than those in a regular preschool and longer hours (up to 50 hours per week). It was also noted that while the salaries for therapists were satisfactory (not paid through CWSD funds), "educators were disadvantaged in this service by lack of superannuation, leave and security."

Comments made by some respondents, primarily from community-based projects, about their salaries and conditions of service included the following:

> "Nearly comparable with Department of Education but no loadings - I lose $4000 this way per year. I worked only four days a week when funds were not available at the beginning of the year and for many weeks there was no pay until it was sorted out."
>
> "Problem of terms and conditions of service when there is no specific award for early intervention workers."
>
> "Problem about determination of experience when using I.T.A. award pertaining to early childhood teachers."
>
> "It's O.K. for therapists but not for educators - No superannuation, no leave etc. We need an award. There is no security."
>
> "Problem is that we pay salaries at I.T.A. rates but need to raise funds to try to meet these costs. Generally several thousand short."
>
> "Staff are paid casual teacher rates, taking account of qualifications. This is currently being looked at by Committee which is examining I.T.A. Award. Director gets Director allowance."
>
> "No one receives allowances etc. for working with disabled children. For example, the Director receives same amount of pay as if she worked in a regular preschool with 20 children (3-5 year olds). The work load is great - I probably work a 45-50 hour week. Staff have a crib break (20 minutes) for lunch, but must be on premises: necessity is with children."
>
> "Lack of permanency a major problem. Uncertainty of funding. Not recognised as Teacher in Charge, and no

> extras for administrative responsibility or a special children's allowance."
>
> "There is some problem with awards etc"

The teacher at a rural early intervention project touched on many of the issues that worried program staff:

> "The Committee has problems with superannuation (they are not against it), sick pay and replacement pay with maternity leave. These should be included in the submission. They are matters that have not been properly organised. I raised the superannuation issue some time ago but nothing has been done. The submission funding does not take into account what has to be done about sick pay (I had 8 weeks off sick) and payments for a replacement person, or maternity leave. The issue of the Committee itself is very important. If the members are competent, then there is no concern. But if they are amateurish, they need advice and guidelines from the CWSD."

Clearly, there is a relatively high level of disquiet among some program staff about salaries, in particular allowances for working with special needs children and administration duties, and in relation to conditions of service (hours worked, continuity of appointment, superannuation and so on). The CWSD Program should note these concerns and ensure that adequate information on rates of pay and working conditions for all staff employed on CWSD projects is made available to management committees, particularly those responsible for the operation of community-based programs. At present, there is evidence of tremendous good will among staff about CWSD projects and it would be disappointing if this enthusiasm was dissipated as a result of inadequate conditions of appointment.

5.8 MODE OF OPERATION

Information obtained from both CWSD files and from material collected during site visits can be used to compile a broad profile of the mode of operation of the 27 projects included in this review. For example, information about the type of service provided by the project is summarised in Table 5.3. This shows that the largest percentage of projects operated as centre-based early intervention programs. However, many of these projects also provided a home-based service; 41% of projects reported that home visits were made. Only one project operated solely in a home-based mode. A small number of projects operated in long day care (11%) and/or child care centres (7%) and a small number (11%) also provided support for children who were being integrated into other (mainly preschool) programs.

TABLE 5.3 Distribution of CWSD Sample Sites by Type of Function (percentages)

FUNCTION	%
Centre-based E.I.	70
Homebased E.I.	41
Preschool based E.I.	22
Integration support	11
Residential care:	
Long term	11
Respite	7
Long day care	11
Child care centre	7
Special School	4
Clinic	4

NOTE: Some Centres had more than one function, so percentages do not total 100.

A total of five programs (19%) operated from more than one site, including a therapy-based clinical service with multiple sites, several itinerant support services operating in a combination of preschools and child care centres, and one rural project that operated in four different types of locations (centre, home, preschool and special school). Many of the projects had more than one function: 15 projects (56%) had one function only (mainly centre-based early intervention); five (19%) had two functions (eg. centre and home-based); five (19%) had three functions (eg centre, home and preschool-based early intervention), while two (7%) had four functions (e.g. residential care, long term and respite, together with a centre-based early intervention program for children from the local community and support for integrated placements for some project children).

Among the eleven projects that made home visits, only five were on a weekly basis; the others were made "as required", usually by the teacher, accompanied, in some cases, by a therapist or another member of the team.

5.8.1 Physical environment

Seventeen of the respondents expressed satisfaction with the appearance of their centre, reporting that it was comparable to other centres in the area, or that it blended in with the preschool building or other houses in the street. Those who were disatisfied complained that their premises were attached to a hospital and as a result, looked institutional in appearance, or that they looked uncared for, inadequate, (a small conference room where equipment had to be set up and then stored away, or the back part of a cold windy community hall, dusty and unattractive with no adaptations for disabled children), drab and reflecting lack of finance, or simply unsuitable. One therapy-based service noted that it selected buildings for its community centres to suit its needs, changing location according to changes in demand for services.

Eight of the centres were licensed (31%) and a further 10 (38%) noted that licensing was not applicable to them. However, one member of the research team expressed some disquiet that project staff were not aware of licensing requirements and may not have realised that their program should, indeed, be licensed. There is a need for the licensing requirements of the whole area of early intervention to be examined and for information about current procedures to be made available to project staff.

Physical adaptations such as ramps, gates and fences, small toilets and showers and widened doorways had been carried out to eight centres (31%). However, no adaptations had been necessary for ten of the centres (38%); five of these had been purpose built, while the necessary modifications were already in existence when the remaining programs were located in their premises.

Sixteen of the centres were either centrally or reasonably centrally located to their potential clients, while five reported that the location of their premises presented some problems in terms of the access of families. A few of those programs which were centrally located noted that they drew clients from wide areas, and that some families had to travel some distance to receive services. Three respondents noted that location was not relevant to their projects. Some form of transport was organised or provided by ten of the centres; four had access to community services transport (HACS), two had a minibus, and a further three were reimbursed travel costs if staff provided transport. In two centres, aides informally provided transport for children who otherwise could not attend. Only eight centres were on public transport. Again, the attention of management committees should be drawn to the need for appropriate insurance arrangements to be made when staff provide regular transport for children.

Most centres had access to a toy library, with five centres reporting that they had their own toy library, four having access to the preschool toys, and two centres noting that they had no need of a toy library as they were very well equipped.

Seventeen of the centres were controlled by a management committee which included parents (65%), teachers (29%), therapists (18%), professionals from other organisations such as FACS, Department of Education, hospitals (29%) and interested members of the community (24%). Seven centres reported that their management formed part of another organisation, such as the Spastic Centre, Preschool Centre, Therapy Centre etc. The remainder did not respond to the question.

The majority of parents were kept informed about the program by newsletter (54%) or informally (62%) as they were involved in its implementation. A day book or communication book was used by 23%, and a few centres informed parents by phone calls or letters.

Over half the programs charged some fee for their services. This ranged from a contribution towards the costs of morning tea, nominal fees such as $1 joining fee and $2 per year, $1 per week optional levy or $3 per week, up to fees as high as $24 per month, and $5 per day (sometimes waived if the family could not afford it). One centre specified that the $10 per term charged went towards the shortfall for travel, equipment and the cost of a receptionist. Only one centre reported that parents were reimbursed for transport costs incurred by their participation in the program.

The procedures followed for checking special equipment used by the children usually involved the therapists (54%), sometimes assisted by staff whom they had instructed. In several centres, the maintenance of such equipment was reported to be ongoing, whenever it was in use, and one centre stated that it was maintained by a handyman. Toys were checked mainly by a combination of aides, teachers, parent or community helpers, and, in one case, a therapist. Ongoing maintenance and removal of damaged or unsuitable toys was carried out by staff while toys were in use.

COMMENTS

Overall, the information reported in this chapter is impressive. On the basis of material collected during interviews and site visits it appears that CWSD project staff are knowledgeable about many aspects of the programs that are considered to be essential for effective early intervention. In their review of services in this field for the Commonwealth Schools Commission, Andrews (1985, p.31) identified eight essential characteristics for early special education and on most of these points, the CWSD projects seem to be satisfactory. For example:

1. Commence as early as possible

Most of the projects (75%) reported that they had no waiting lists or had a waiting period of under three months, while only one project claimed that some children had to wait more that 12 months to join the program. This result suggests that special education services fairly readily: i.e., families are able to obtain help for their disabled children relatively quickly.

2. Actively involve the parents in teaching and decision-making

Projects vary in the degree to which they involve parents in teaching and decision-making. Parents are generally not present during assessments though they contribute information. They are also on the management committee and, in some community-based projects, were actively involved in the establishment of the program. However, comments made during interviews suggested that not all program staff encouraged parents to be actively involved and, in some cases, felt that parents would prefer not to take an active role. In addition, few projects were able to provide counselling for parents, though about half were able to provide some form of help and almost all reported that they referred parents on to other agencies, if this was considered to be necessary. Few provided any type of training program for parents on a regular basis. While there appears to be widespread awareness of the rights of parents to access to information about their child's program, and about the need for families to be involved in the program, the actual implementation of strategies and arrangements to fully involve parents, to support them and to give them the skills they are going to need, both now and in the future, may be less satisfactory. This inadequacy seems to result, in part, from a lack of understanding by some project staff, as well as from a lack of time and, possibly, skills. This is an area that should be addressed by the CWSD Sub-committee, to see if any procedures can be implemented that will help to maximise the impact of CWSD funds on parents and families, as well as on the child who has a disability.

3. A structured approach to curriculum and teaching
4. Objectives derived from normal developmental sequences
5. Frequent assessment, with objectives derived from assessment results

These are areas where teaching staff appeared to be well informed. Most projects had access to appropriate curriculum

These are areas where teaching staff appeared to be well informed. Most projects had access to appropriate curriculum material and appeared to understand the need for a structured teaching program, use of teaching sequences based on normal development and the need to base teaching objectives on frequent assessments. The recent publication of the curriculum documents for students with severe disabilities should contribute to effective teaching in CWSD programs.

6. Use of an integrated interdisciplinary staff

While most projects had access to therapists and other professional support, it was not clear from comments whether teaching programs were implemented in a manner that could be described as interdisciplinary. No doubt, a few programs would be able to show that this coordinated and integrated approach to program development and implementation did occur. However, this situation is probably fairly rare. The CWSD Sub-committee should endeavour to identify strategies that will facilitate and encourage project staff, both teachers and therapists, to seek to coordinate their services more effectively.

7. Curricula that are preparatory to school entry
8. Follow-up support

Where appropriate, programs appeared to be aware of the need to coordinate their programs with the curriculum requirements of the child's next placement, and most centres had procedures in place to help the children in their transfer to the next educational program.

Other recommendations related to material contained in this chapter are set out in Chapter 7.

CHAPTER 6

CWSD PROGRAM

A major aim of the review was to examine the operation of the CWSD Program in terms of its impact on the projects that are funded. Questions were asked about how the project staff first learned about the CWSD Program, the importance of CWSD funds for the operation of the service, the major strengths and weaknesses of the CWSD Program, any changes that should be made, the most successful and least successful aspects of funded projects, the type of help that is most useful and the major impact of CWSD projects on the children involved and their families. Information obtained from these questions is summarised below.

Most respondents first learned about the CWSD Program when they began to work at the centre, because successful applications had already been made over previous years. A small number of those who had not already heard about it saw an advertisement about the program in a newspaper (15%) or were told about it by colleagues from government agencies, such as the Department of Education (e.g., "The Principal of the Special School"), FACS (19%) or from other professionals, such as therapists or social workers (15%).

Almost all of the projects reported that CWSD funds were crucial for the operation of the program. A majority (63%) claimed that the program would cease if funds were withdrawn, though some respondents indicated that the program would operate at a reduced level (19%) or change in some way (7%). For example, respondents indicated that services located in several residential care units would continue if CWSD funds stopped, but with no educational component. A rural respondent from a hospital-based project commented:

. No home visits
. No Playgroup
. No preschool visits
. No follow-up

The staff member interviewed at a metropolitan long day care centre found it was very upsetting to discuss discontinuation of CWSD funds. The program at her centre would fold in two years, if funding ceased. The educational component would stop immediately but the day care would continue for two years to the families who were already promised places. After that time, the whole program would end.

On the other hand, it was reported that a large therapy service would probably find resources to continue the service if the grants ceased; the CWSD funds had had a seeding function and the value of special education to the overall service was now accepted.

6.1 Major strengths

The most frequent response to the question about the strengths of the Program referred to the fact that the CWSD grants enabled a service to be provided which would otherwise not be available to the target group of children; 56% of respondents mentioned this point:

> "Children with severe disabilities would otherwise not have opportunities that mild/moderately disabled children have"

Two respondents referred to the support provided to parents and children through CWSD funds. The seeding function of CWSD grants was mentioned by one respondent from a project which had, through the CWSD Program, been able to demonstrate the need for early intervention for children with severe disabilities to its management committee. This "demonstration" function was also mentioned by respondents from hospitals for children with severe disabilities:

> "Education has become as important as the medical side"

> "Provides institutionalised kids with education in centre and regular settings"

The feelings of many respondents was probably echoed in the words of one person from a rural project.

> "Its major strengths... are that it exists with flexibility to work with therapists within the Education Department"

One respondent commented on the value of the support provided by CWSD administrative staff:

> "The major strengths of the program are that it gives the money and provides the support (e.g. Judith Langley). She has visited once, in the early days, and the teacher felt that she needed the feedback that the program was operating well. The teacher can phone Judith when necessary."

6.2 Major Weaknesses

Various matters were raised by respondents in relation to the major weaknesses of the CWSD Program. These included the following:

(a) Insufficient funds (44%)

It is probably not unexpected that many respondents referred to inadequate levels of funding. For example, a respondent from a metropolitan residential care unit thought that the major weakness of the program related to the fact that there was "not enough time for each child", "more staff = more funding." She commented that "these kids are profoundly handicapped - a very difficult task" Similar comments were made from several rural early intervention projects:

> "Insufficient funds for adequate contact; also lack of time - again a money problem. No time to assist with integration into preschool. No time for individual counselling.
>
> "Inadequates funding for personnel - need for more frequent child contact."
>
> "Not able to run program as would like. Require more time for aide."
>
> "Limited time and limited funding for appropriate equipment."

Five respondents (19%) stated that they would like to see an increase in the hours of operation of their services, or an increase in the number of children and/or number of staff. A long day care centre was limited in the number of children with disabilities who could be accepted because of licensing requirements. Other comments related to inadequate funds included:

> "We need greater flexibility so that children can attend more than three sessions a week, especially the children who are being integrated."
>
> "This should be a 5 days a week service."
>
> "Continuing problem of keeping a balance between providing an exemplary program and the small amount of money that is available."
>
> "More money for integration and home visits. More time for parent training programs."

(b) Funding procedures:

. Uncertainty (44%)
. Guidelines (26%)
. Timing (11%)

Difficulties associated with annual submission-based funding arrangements were mentioned by many respondents. For example:

> "The doubt whether or not funding, will be granted (following application for funding), also high administration costs."
>
> "Uncertainty of funding. Huge funding submissions, time consuming. Evaluation of children by other disciplines demanding. Delayed funding this year. Too late being told whether future funding is available. This is terrible for staff and results in limiting taking on other children. There is value in assessing children on a function basis for the submission but terribly time consuming."
>
> "The weakness is that they don't provide any guidelines, especially with people who are new to this area of teaching. The teacher would also like help with the submission for funding."
>
> "dependence on yearly grants creates insecurity. Shortfalls in funding:
>
> - shorter terms
> - less comprehensive programming than is desirable
> - higher administration costs."
>
> "administration costs are not included and Parents and Friends group must raise funds to pay these. Also, there are higher administration costs because it is an annual grant. Anxiety is heightened in the parent group because the grant is annual and insufficient."

(c) Definition of "severe disability"

In relation to the CWSD Program guidelines, many respondents commented on the problems they encountered in relation to the definition of "severe disability." For example:

> "We don't know what they consider a severe handicap. Children in the project change over time and they have to be carried after 4 years of age in isolated areas where there are no other services."

Many of these concerns were expressed in the following comments from respondents at two rural, community-based early intervention programs:

> "Instability of job - annual funding leads to considerable uncertainty: therefore, cannot plan ahead. No formula given for funding. We do not wish to label the children as CWSD - it limits their potential."

> "The major weaknesses of the Program include the very few guidelines and inconsistencies (e.g. definition of Severely Handicapped). Also, we never know when funding is available or how much - can't plan for this year or next year. We should be able to visit the homes of some children and some families. We have had to cut down from full time program to part time because of funding decreases."

Issues related to funding, including delays in the arrival of cheques and, more importantly, threats to the continuance of funding at previous levels, or, indeed, total elimination of a grant, are a source of continual anxiety and, in some cases, anger to those who have struggled to set up a service which they believe is essential for the children and families involved. Evidence of this passion is in a letter (Attachment E) from one of the projects visited for this review which was published in the Newsletter of the NSW Early Intervention Association (August, 1990).

Other Issues

One project referred to problems related to the demands of the CWSD program for information and for the collection of unnecessary data. It was argued that this undue focus on testing and test scores could lead to the actual participants (the children) feeling rejected. Another program also commented on problems associated with data collection:

> "Lack of specific directives re expectations of what the funded service is to provide and what records kept and evaluations carried out etc."

A related issue identified by several respondents concerned the difficulty of predicting the children with severe disabilities who would be enrolled in the program in six months time:

> "It is very difficult to say which and how many children will be in the program six (6) months ahead.
>
> Number of Children: e.g. 1989 increased from 5 to 14 from time submission was written to present.
>
> Which children: often referred at birth if diagnosis certain, e.g., SP or DS (are these necessarily severe, must presume so), but more uncertain if children referred say birth to 12 months or even up to 2 years when history and development are unknown and hence likely rate of progress undeterminable in short space of time before submission due. So, you need $10,000 but know you'll get $2,000/child, so you pick your five most severe children and hope you don't get too many more."

One respondent saw lack of inservice as a major weakness of the CWSD Program:

> "we are very isolated here and badly need inservice training locally, or paid fares and accommodation to Sydney."

6.3 Suggested Program Changes

Among the various suggestions made concerning changes that could be made to the CWSD Program, the most frequently cited (41%) concerned improvements in funding procedures, including earlier notification of continued funding and provision for longer term funding:

> "There should be forward commitment of funds."
>
> "We need to be notified in November of next year's funding so that we can begin to plan!"
>
> "We need to know earlier whether we are getting the money - should be informed by November 30th. The teachers don't know whether they have a job next year. We seem to get less and less funding from this Program. We don't know what the funding is based on - per capita, or what?"

> "We would like to see provision for on-going funding for well established projects so that the children have security of placement and staff continuity."

> "Security of funding - Possibility of making long term arrangements."

The 1989 Administrative Guidelines refer to the possibility of forward commitment of CWSD funds, but there was no evidence that such commitments had been made in the information collected for this review.

Reference was made by some respondents to a need for more help from CWSD or other sources in relation to issues in program implementation and to changes that could be made to improve the program currently being offered by their service. Several respondents also suggested that more inservice and professional development activities could be provided:

> "Changes to the Program could include more personal contact, with practical ideas from the specialists. It would be good to have inservice training to make more contact with others in the field of early intervention, or the possibility of visiting other programs: e.g., travel to Dubbo for the day, or Lithgow."

> "We need a specialist early intervention conference for staff interested in severe disability. We are interested in early intervention for these children, home-based programs, working with parents - NO classrooms, and NOT school-aged children."

One respondent mentioned a more specific need: "greater availability of special equipment such as computers."

Problems encountered in the preparation of CWSD submissions caused three respondents to suggest that greater assistance should be provided in this and other aspects of the Program's operation and administration:

> "The teacher would like help with the submission for funding."

> "There should be more support for the Committee and more help with submission writing."

> "They could send somebody to help the Management Committee because they flounder."

Most of the other topics mentioned here were also raised in the previous section, referring to the major weaknesses of the CWSD Program.

6.4 Most Successful Aspects

Topics mentioned by respondents as being the most successful aspects of the Program tended to be concerned with children's progress; the development of independence, more appropriate behaviour, play and communication skills and access to a normal environment.

Parental contact with staff and involvement in the child's program was also seen as a successful aspect of CWSD funded projects. Some typical comments include the following:

> "That it exists!"
>
> "People can see that these children have a right to education - including parents!" (from a long term care residential unit for children with severe disabilities)
>
> "To see the children progress so well. Also the support to parents is important. It's good to see the change in them!"

Several respondents focussed particularly on the impact of their project on the parents:

> "The successful aspects are that it offers a service to the children and parents and gets the parents involved. It offers a resource to parents who haven't had it before."
>
> "The parents are extremely enthusiastic about the program. They are being offered positive advice on their children."
>
> "Looking at it from the parents' point of view, it helps them accept their children, especially fathers. Providing practical support to parents in the day-to-day management of their children gives them hope - they are often hopeless and isolated."

Other comments about the successful aspects of the Program referred to integration:

> "Our integration program is highly successful in terms of the program's goals - good rapport with preschools."

> "The integration element is the most successful, where all staff and children have input into the disabled child's development."

> "The integration element of the program - the child has a right to education."

6.5 Least Successful Aspects

In contrast to the focus on the positive impact of the CWSD Program on children and families in the previous section, respondents here referred mainly to issues associated with the operation of the service and the achievement of program goals.

> "Not enough time for each client. Funding is limited. Also, the set up is not conducive to group work - it is mainly one-to-one or two adults working with a child. There is no time for evaluation and research."

> "The limited hours that the group is operating."

> "Can't do as much as we would like to do."

> "Limits placed by funding - would like more home visits."

> "The funds are not really adequate. The program needs more equipment, and needs to operate for more hours or more days. There is not enough time to organise equipment before or after sessions, or to talk to parents. The other difficulty is that there are not enough guidelines, initially. The difficulties are coped with by being flexible and adaptable."

> "The least successful aspects are that the program cannot get access to other professionals and that the premises are inadequate."

Several comments were concerned with difficulties encountered in involving parents in programs: apparently these problems were among the least successful aspects of some programs:

> "Efforts to involve parents more in setting objectives and reinforcing activities at home."

> "Too rushed - not enough time to spend with parents, especially distraught mothers in crisis situations."

> "Some parents have to travel up to one hour each way."

Some specific issues were raised, reflecting particular needs and problems in some programs. For example, one rural program which operated in part of a child care centre noted that

> "while the most successful aspects of the program are that they are integrated into the preschool and have access to a normal environment, and can share equipment, the least successful aspect was that they had no area that was their own."

Other comments included:

> "We need a physio."

> "Problem of distance - STD costs!"

Or a more worrying comment, also mentioned in answers to other questions:

> "Handling the Committee; educating them to manage the program. Nobody knows how it should go!"

One centre raised the issue of the age at which children could no longer participate in the CWSD project:

> "Children at 4 can no longer be helped. But schools do not always accept them. We were not told about individual program grants for children over 4 years."

Several references were made here to issues raised earlier, in relation to the major weaknesses of the CWSD Program, including uncertainty about guidelines and delays in advice about continuity of funding.

6.6 Adequacy of funds

A majority of the respondents indicated that the funds received from the CWSD Program were not always adequate. Problems mentioned here included difficulties in funding staff positions, problems in covering the maintenance and updating of equipment and resources, and need for funds for administration costs and daily running expenses. One centre responded to this question with the following:

> "No. We would like funding to:
> * Extend the service to home visits.
> * Aquire specialised expensive equipment.
> * Cover administration costs.
> * Release staffing so that program staff can participate in more comprehensive evaluation and planning."

Another program stated:

> "Salaries are adequate; just adequate. $1400 is not quite enough for daily running costs. Extra fund-raising is needed."

6.7 Major Difficulties in Implementing Projects

The major difficulties identified by respondents in relation to the implementation of projects funded by CWSD grants tended to reflect the issues raised in earlier discussions of problems and difficulties.

The inadequacy of funds was mentioned by more than half of the respondents (52%), uncertainty of funds by 30% and delay in receipt of grants (9%). Other difficulties mentioned by several different programs included:

problems in finding suitable staff	(4 programs)
distance travelled by some families	(2 programs)
access to professionals	(2 programs)

Other issues mentioned were often specific to those projects, for example:

> ""Bus assistants are a problem. We rely on volunteers. Teacher's aide shouldn't have to do it."

> "Re-working plans to deal with less money than requested - reducing services."

> "The funding is administered by a parent."

> "Allocating funds to accommodate new children without discharging children already in the program."

Again, problems associated with inexperienced management committees was mentioned here:

> "Management Committee has problems with funding. Secretary doesn't get the minutes out. Previous Committee was good."

Most programs coped with these various difficulties by fund raising (27%), by ensuring flexibility in programming (26%), by reducing services (15%) or by "putting up with the problem" (37%). For example:

> "We cope by not making plans for the future and telling parents that the service is only on a year-to-year basis."

> "By altering timetable, reducing time spent with each child."

> "As best we can - Committee will 'fund raise' to assist in the best way it can."

This last comment was made by a respondent from a rural early intervention program who probably represented many of his or her colleagues with the following comment:

> "Why should funding be reliant on the ability to write submissions? Why should these have to be redone each year? It would be nice if it were, say, every 5 years."

6.8 Assistance from CWSD Staff

Respondents varied in their answers to the question about assistance from CWSD staff. Only one indicated that the centre had received a great deal of assistance, while a further 13 (45%) outlined a number of different contacts, including visits by CWSD consultants to advise on programs and on the preparation of submissions and telephone calls about various subjects Only four respondents reported that no assistance had been received from CWSD staff and two of these were part of a large metropolitan service which may have had some direct contact. A further three did not respond to this question. Overall, a majority of respondents had received at least one visit (69%), and this, together with telephone contact, appeared to be adequate.

Direct references to CWSD staff were generally positive. The most useful assistance involved practical help in the implementation of programs (41%) and assistance with staff development (37%). A number of respondents requested more inservice for staff working in CWSD projects; conferences, workshops, seminars and training for aides. Help with writing submissions and interpreting the criteria for funding was valued by seven centres (26%), with a further three seeking advice on the availability of resources, and information on where to seek alternative funding sources. One centre noted the usefulness of equipment and library services, and another felt the need to exchange ideas regarding new equipment ("What is new on the market"). Specific comments included the following:

"Judith Langley visited once - spent day writing up programs - gave some ideas with programming. It was helpful."

"One visit from Judith Langley. Beneficial. Information about running professional development seminars."

"General assistance - getting funding and writing submissions. Visit from staff - they sorted out the funding delay."

"Judith Langley visited for one hour only regarding all the program. Colleen Hore - re getting it in on the day. We do three submissions here and three for Taree. Darni was approachable, brought aids and videos."

"Yes, Consultant visited - Catherine Brock. Telephone - Colleen Hore, Glen Davarson re funds and cheques. Most useful are books and program ideas, and visits."

"No. One visit from Darni. Attended conferences but classroom orientation irrelevant. An early intervention type conference would be very useful - share ideas with funded projects. Early intervention, multiple disabilities - need to target specific groups of clients."

"Judith Langley very helpful but not enough. Colleen very helpful on phone. Management Committee needs help."

"Darni visited last year - visit only. We need regional inservicing."

"We have good contacts with Colleen Hore. Inservice? Talk about it a bit but no one does it. If any of us go, we all need to go - not just one."

"Darni Pather came - discussed program and staff development needs. Most useful would be staff development for aide - career opportunity."

"Darni Pather. Most useful assistance - writing a successful submission."

"No - felt it was not required. Darni did advise funding - $2,000 per child. No funds for transport. Useful to know about availability of resources."

"Visits are the most useful type of assistance and information of what one is doing right and advice on what is being done wrong. Advice on an appropriate timetable is also needed - what proportion of time should be spent on programming for children and on parent interviews."

"Yes, we have had an annual visit from the consultant and advice over the phone. We need advice and assistance, e.g., for preparing submissions. Equipment and library service. (But service is poor.)"

> "Many phone calls to Colleen Hore and to Judith Langley. Good that she was at the seminar. We need personnel help here. For a beginning committee, the guidelines are too brief. We need a lot more information re pay, workers compensation, tax deductions. First 12 months is horrific."

6.9 Major Impact of CWSD Projects on Children

In considering the major impact of the CWSD project on the children involved, a majority of respondents (56%) mentioned factors associated with children, including marked improvements in their development, in the skills that had been achieved and in appropriate behaviour.

> "Most children have made great gains. Would not have happened without this."

> "All children have progressed well, since attending the service, according to parents, caregivers as well as therapists."

> "Great improvements in children's development and the parents relief at some support and guidance."

> "Enhances child's development. Raises child's self esteem and level of parent's perception."

One respondent listed some specific improvements that had been observed, following participation in the CWSD project:

> "Improvement in the area of:
>
> *separation from parents
> *independence
> *communication skills
> *attending skills."

Other respondents referred to the impact of CWSD projects in terms of the provision of an educational program and experiences:

> "Receiving a program - wouldn't have otherwise."

> "Given them early intervention when none available. For example, in one family with several disabled children, the one who had early intervention is much better than the one who started it at 3."

> "It has provided age-appropriate educational experiences - only chance the children have."

> " "Having the opportunity to attend preschool and being accepted at home and with peers."

> "The major impact of the CWSD project on children is that they have a service which they didn't have before. It's too soon to tell if the children who go to preschool after the program perform better."

6.10 Major Impact of CWSD Funds on Families

Respondents' comments about the impact of the CWSD project on the families involved referred most often to the support provided by both program staff and other families:

> "Tremendous support to worried parents and marked improvement in the children and in their integration into preschool and school."

> "Having someone to contact for information and assistance, support from staff and other families, direction for child's program."

> "Something positive is finally being offered to their child. They are no longer totally responsible for their child's therapy."

> "Parents find it helpful and it provides them with support and hope for the future."

> "Support to parents and understanding of development of children. Involving the fathers as well - we encourage them to come if not at work."

Other respondents talked about the practical help that could be given to families:

> "Better translation of therapy goals to parents. Also more help available with choices about preschools, playgroups etc. Transition points are better handled."

> "Professional support for their special needs. Information and co-ordination of services. Respite care."

> "Change in attitude - more optimistic/positive."

These comments all reinforce the very strong overall support for the CWSD program among all those interviewed for the review.

Finally, respondents were invited to make any other comments about the operation of the program. Among the nine (33%) responses provided here, the following issues were raised:

1. Inservice Needs

A teacher in a project located in a metropolitan residential care centre referred again to the need for CWSD inservice activities, and to the need for opportunities to be provided for staff to keep in contact with other Health professionals.

2. Limitations in Staff Skills

The teacher in a small rural early intervention centre said that she was aware of her own weaknesses and limitations in providing programs for all of the children. For example, she did not sign for a child with a hearing impairment. However, the parents expected her to have all the required skills, or to access them in some way. There was an ongoing need for her to be able to draw on other resources, such as therapists, as the need arose.

3. General Satisfaction with Service

One respondent commented, in the final question, that "benefits of early intervention to the children and their parents are obvious."

4. Need for an Administrator

A teacher at a small rural program commented on the need for a part-time co-ordinator to run the centre. She was the only teacher on the staff (she had an aide) and was often called to the telephone. She had had to reduce the program to five mornings and only two afternoons to cope with these additional demands.

5. Distance

One respondent enclosed a map of the area covered to illustrate the geographical isolation and vastness of the area and distance covered within the project. A copy of the map is appended (Appendix). The problem of distance was also raised by several other respondents who were concerned about the impossibility of the demands placed on some families who had to travel long distances to get access to a CWSD program.

6. Uncertainty of Future Funding

The major problem for a city long-day care centre concerned the uncertainty of future CWSD funding and the need to plan for the future of the project. As noted in an earlier section of this report, this respondent was worried about the procedures that would have to be followed if the funds were discontinued. She was particularly concerned that arrangements that were made with parents would be fulfilled.

7. Integration of ESEP and CWSD Programs

Two respondents raised the issue of the integration of the two programs: ESEP and CWSD. Both argued that these two programs should be more closely linked within a program concerned with "early intervention services" or "early education for children with disabilities." One respondent queried whether the focus should continue to be on children with severe disabilities, since, in her view, the least well served group of children with special needs were those who were mainstreamed or in integrated placements.

8. Program Operation Times

Reference was made to two aspects of program operation - hours per day and weeks per year. Both comments were made by staff at long-day care centres. In the first case, the issue of funds being available to cover longer hours was raised "Parents should be allowed to work." A similar question was raised by the second respondent who commented "only 48 weeks a year!"

9 Predicting Future Enrolments

The demands associated with preparation of the CWSD submission, to predict the number and level or type of disability of children likely to be enrolled in the program in six months, was again raised in one comment.

This problem is of particular significance for projects operating in defined rural areas where no other services are available, if all places are full in the project.

COMMENTS

The material presented here confirms that the CWSD remains a very important source of funding support for projects that provide an educational program for young children with severe disabilities in this State. Some of the problems that continue to concern staff relate to the definition of "severe disability" and related eligibility issues, adequacy of funds, problems in preparation of submissions and delays in receipt of grants. Other areas of concern relate to conditions of appointment of teaching staff, training of aides and professional development of all staff. Recommendations to the CWSD Sub-committee on these issues are included in the next chapter.

CHAPTER 7

DISCUSSION

In the introductory sections of this report (Chapter 1), three broad aims and a set of specific objectives were identified that it was hoped the review of the CWSD Program would attempt to answer. In the following discussion, the questions raised by these aims and objectives will be addressed and some conclusions drawn on the basis of information presented in earlier chapters of the report. Where appropriate, reference will be made to matters that should be drawn to the attention of the Co-ordinating Committee of the Commonwealth Special Education Program. Reference will also be made to issues that may be of relevance to those involved in implementing CWSD projects and to the families of children with severe disabilities who may or may not be associated with a CWSD funded project.

7.1 Who is receiving help from the projects funded by the CWSD Program?

From information presented in Chapter 5, the following general statements can be made about the children who participated in CWSD funded projects during 1989.

7.1.1 Age

Over half the children (56%) were aged between 24 and 48 months. Very few (3%) were under 6 months and only 9% over 60 months (see Table 5.1). There appeared to be some uncertainty, both in the guidelines for the Special Education Program itself and the CWSD program in particular, as well as among some of the project staff who were interviewed, about the age of children who were eligible to participate in CWSD projects. The CWSD Program guidelines state that students in the age range 0-18 years are eligible for funding. However, the focus of this review was children in the early childhood level. The Early Special Education guidelines state that children must be in the age range 0-6 years. Among staff interviewed for the review, there seemed to be some uncertainty about this; some indicated concern that a few children were "over 48 months." Apparently, pressure is exerted on staff in some projects not to enrol children over 48 months because, at this age, they should be enrolled in a special school or, alternatively, moved on to a fully integrated setting. In the light of this uncertainty and inconsistency in the application of eligibility requirements across projects in different types of settings and in different regions of the state, it is recommended that specific guidelines be formulated to define the children who are eligible to participate in CWSD projects, particularly where alternative schooling options are available.

7.1.2 Disability: type and level of severity

On the basis of the somewhat limited information provided by those interviewed on selected project sites, it appears that the disabilities that occurred most frequently among children participating in CWSD projects included those involving movement (physical impairments), and intellectual impairment (including some children with Down Syndrome and others, whose intellectual difficulties were not associated with this condition). In addition, a number of children were described as having "multiple disabilities."

One of the problems identified in the review that was associated with the question of type of disability concerned the identification of children whose problems could be described as "severe" in nature; i.e. those eligible to participate in a CWSD project. Some effort should be made to provide clear and simple guidelines for criteria to be used to identify this target group of children. One possible approach would be to use the strategies developed by the Australian Bureau of Statistics in its 1981 review of people with disabilities. This procedure involved identifying the aspect of function that was affected by the impairment (vision, hearing, movement - upper or lower torso, language), or the condition that caused the difficulties (epilepsy, disfigurement, pychiatric disturbance). The various areas of activity that could be affected by the disability were then listed (self care, movement, communication, schooling) and a scale identified by which the severity of impact of the disability condition on the individual's daily activity was assessed, e.g., level of impact and relative need for assistance: none, mild, moderate or severe). An adaptation of this scheme is included in a chapter by Bochner in Ward, Bochner, Center, Outhred and Pieterse (1987) and this approach was used as a basis for developing the questions included in the survey of children involved in early intervention in New South Wales (1989) that was carried out concurrently with this review. It is recommended that the Committee identify clear and simple guidelines that can be used by staff implementing CWSD projects to identify children whose impairments are severe in nature and who are therefore eligible to participate in projects.

7.1.3 Location of projects and children

Only three (11%) of the projects (and 13% of the children) included in the survey were located in residential institutions. In contrast, 19 projects (70%) were located in early intervention centres, and the remaining programs operated in preschools, long day or child care centres and clinics offering therapy services. Only one project was wholly home-based but 14 (54%) provided some component of the program in a home-based mode or occasional visits to children's homes.

(a) Children living at home.

It is clear that some families will continue to require services of an early intervention nature to be delivered in the home. Problems with transport, distance, the type and severity of the child's disability and the resources of the family to cope with the child's difficulties are likely to influence any decision to provide home-based services in preference to other types of help. The need for such services may be short-term, reflecting the current needs of the child and resources of the family. However, in view of the difficulties that many of the projects reported in this review in relation to finding staff and resources to support a home-based program, it is recommended that the Sub-committee give priority to programs that provide centre rather than home-based services, but ensure that sufficient resources are available for some flexibility, where families are unable to attend a centre.

(b) Children in long day or child care centres.

The relatively small number of children who received a program within a long day (11%) or child care centre (7%) of projects suggests that few children with severe disabilities currently have access to these services. In the light of increasing community demands for access to child care services of some type, it may be timely for the Sub-committee to review the availability and level of provision that is currently provided for parents who have children with severe disabilities and who need some form of long day care on a regular basis. As early intervention services have expanded, largely as a result of the efforts of groups of parents working together to establish services in their communities, it is possible that the needs of some families for other types of assistance, such as long day care, have been neglected. It is therefore recommended that the Sub-committee review the needs of children with severe disabilities and their families for services of a child care nature, with consideration being given to providing seeding grants to support the establishment of such services in existing centres or in new services specifically catering for this group of children and their families.

(Examples of several such projects were included in this review).

(c) Children in long-term residential care.

While relatively few children involved in CWSD projects were living in long-term residential care situations and in the light of continuing reductions in the numbers of children receiving such care (e.g., Bochner & Ward, 1990), it must also be acknowledged that there will continue to be small numbers of such children who will require such forms of care and will, therefore, need access to educational programs within these settings. Indeed, it was the urgent need of this group of children that prompted the introduction of the CWSD Program.

children that prompted the introduction of the CWSD Program. However, the number of children involved is steadily decreasing, and the quality of the services provided from those who continue to live in residential care has improved. A dilemma faces programs such as the CWSD, in relation to requests to provide funds to services that are, in some ways, outdated. Should grants be made to programs which are not congruent with current community beliefs and values about the needs and rights of children with disabilities? Should funds be allocated to government or, in some cases, non-government organisations to supplement services such as early intervention which should be provided within the resources already available to these agencies?. It is suggested that the Sub-committee review its priorities in relation to funding projects within long-term residential care units, to ensure that it is not supporting programs which, in some respects, are outmoded in terms of current community standards; or programs operating in facilities operated by large organisations which should have access to funding to support early intervention services from within their own resources.

7.1.4 Minority Group Representation

While no data were collected on the background of families associated with projects in terms of ethnicity or Aboriginality, it was evident in responses to interview questions that there may have been a relatively low representation of children from non-English speaking families and children from Aboriginal backgrounds in terms of their numbers within the wider community. Certainly, some metropolitan services did have large numbers of children who came from minority group backgrounds. However, it is of concern that, since early intervention services are often established on the initiative of groups of parents who are able to become actively engaged in community-based projects, care needs to be taken to ensure that access is guaranteed for other families who may be more peripheral members of a community, either as a result of recent arrival in an area, lack of English, lack of familiarity with local customs or lack of access to informal local community networks. It is

Program guidelines that, on the basis of equity, organisations providing services at local, regional or State levels ensure that all families who have children who are eligible to take part in CWSD projects receive information about the service and are encouraged, and if necessary assisted, to take full advantage of these opportunities for their children.

7.2 What form of service is being provided or supported by CWSD funds?

Material in answer to this question is derived largely from, information collected during site visits and interviews and the comments are based on information contained in Chapters 5 and 6.

7.2.1 Program Aims

The overall aims of all projects surveyed were concerned with improving developmental outcomes for children with severe disabilities who were below school age. Concerns about the definition of "severe disability" and uncertainty about the specific definition of "below school age" have already been discussed (see 7.1.1 and 7.1.2). All the projects had the goals of increased independence and enhanced self esteem implicit in their aims and objectives.

7.2.2 Priority areas

The CWSD guidelines identified three priority areas for the program:

- children receiving inadequate services
- programs involving parents
- practical solutions to students' needs

The following comments can be made about these priorities.

1. Children receiving inadequate services

As would be expected, almost all of the projects reviewed claimed that without the CWSD funds, the project would cease to operate. The truth of this assertion is evident in several comments about services which did, in fact,cease, when funds either failed to arrive on time or were depleted before the end of the school year. It is difficult to see how most of the projects run by community-based groups would operate without CWSD funds, though many of these services could possibly be included among the programs offered by possibly be included among the programs offered by developmental disability teams. Government schools could (and, indeed, do in some regions) provide some services of an early intervention nature. In time, the generic service systems may assume responsibility for the programs that have been established by enthusiastic and hard-working parent and community groups. Indeed, this is happening to some extent in local areas where active parent community groups have not formed and the Department of School Education has introduced early special education programs. Meanwhile, it is suggested that the Sub-committee should continue to support community-based program initiatives, since they generally provide services where none exist, and, in most cases, actively involve parents of the children in many aspects of the teaching program. However, in relation to CWSD projects located within facilities operated by government departments and large charitable organisations, the Sub-committee should give consideration to providing funds to support new initiatives, as a seeding function only. Once the need for the service is recognised, the umbrella organisation should accept financial responsibility, in line with changing needs and community expectations.

(2) Programs involving parents

The majority of projects actively involved parents in teaching and in other aspects of the program. Not unexpectedly, parents were least involved in long-term residential care settings, in some cases because the family lived at some distance from the institution and in other cases because of lack of interest (possibly exacerbated by the distance factor). However, a few projects appeared to have little interest in actively involving parents, seeing their contribution as more peripheral in the teaching process. Others reported that their parents were not always interested in being actively involved in children's programs. Undoubtedly, some parents prefer not to be involved, are under too much stress to participate, or may feel inadequate, unable to help, or overwhelmed by teachers, therapists and other staff. However, the CWSD Program should take an active role in ensuring that, as far as possible, project staff try to involve parents in all aspects of the program. This may be particularly important with some families, including those from minority groups, who are not accustomed to the idea of actively teaching children at home.

Questions about parent involvement should be included on the CWSD application forms and priority should be given to professional development activities concerned with this topic. Care should be taken to continue to fund projects that actively involve parents. Consideration should also be given to introducing a Newsletter or similar information sheet to be distributed at regular intervals to participating programs with information related to this and other relevant topics. It is therefore recommended that the Sub-committee consider the following procedures to ensure that parents are involved in CWSD projects as fully as possible.

1. Include questions about parental involvement in the CWSD application forms.
2. Support professional developmnent activities concerned with parental involvement.
3. Continue to give priority in funding decisions to programs that actively involve parents, and
4. Consider the introduction of a Newsletter or similar information sheet that could provide a means of informing projects about matters related to the effective involvement of parents in their children's programs.

(3) Practical solutions to student needs

All of the projects included in the review were involved in the provision of direct services to children, so, to this extent, they were providing practical solutions to the children's needs. However, the projects surveyed varied widely in the solutions they had devised for some of the problems that are encountered in most projects that work directly with children and families. Some staff, particularly those associated with programs that were newly established, would have benefitted greatly from an opportunity to observe other, well established and successful programs in operation, or to have had access to information about some of the procedures that had been developed within centres that were similar to their own.

Based on comments received during site visits, it was evident that the CWSD Program field officers and other resources had provided valuable assistance to a number of projects. However, in relation to the field officers, it was also apparent that they were not able to visit all the program sites often enough to be able to provide the level of assistance that was sometimes needed. Reference was made by two respondents to library and other resources available through the CWSD Program (Student Support Services Resource Unit?) but no other references were made to these sources of information and equipment. It is therefore suggested that a review should be carried out of all the resources relevant to CWSD programs that are available through the NSW Departments of School Education, Health and Family Community Affairs. Information about these services should be provided to project staff. This should ensure that all projects have access to information about available resources. It is therefore recommended that the Sub-committee consider developing a range of procedures to ensure that information is made available to all projects about resources available within various government departments; and about successful projects, assessment techniques, teaching programs, data collection instruments and so on; opportunities should also be provided to enable staff to visit successful projects and to attend relevant inservice courses, conferences and other professional development activities; the CWSD field officers should continue to be available to provide direct assistance to projects that require help.

7.3 Program Operation and Implementation

Overall, data collected during the review about program operation and implementation suggested that the quality of projects was very satisfactory. Most respondents showed a high level of awareness of the procedures that should be followed in the assessment of children and in the development and implementation of programs. Any reservations that were felt by the research team related to:

1. Lack of time and resources
2. Limited or inappropriate preservice training among teachers and aides.
3. Staff conditions of appointment
4. Unsuitable premises
5. Management committees

7.3.1 Lack of time and resources

Apart from a few services that were located within larger organisations, most of the projects appeared to be overstretched in terms of the demands made on staff. This trend was more evident in smaller programs, where staff were often appointed on a part-time basis only. Several comments were made about hours having to be reduced because of lack of funds, though the demands made on staff did not diminish. Preparation time, and time to talk quietly with individual families, was often lost in the pressure to keep the project operating in the hours that had been planned. In this sense, the service provided by many community-based programs could be regarded as very cost efficient, but these savings were often made at the expense of staff, as much as children and their families. The Sub-committee is urged to ensure that the level of funding provided to projects, particularly those associated with smaller, community-based organisations, is maintained at a level that is sufficient to keep the service viable and does not result in an excessive burden on staff responsible for its operation.

7.3.2 Limited or inappropriate preservice training among teachers and aides

One of the problems associated with the introduction of a new form of educational service, such as early intervention, results from the lack of appropriately trained teaching staff and a shortage of teachers with experience in this area. In fact, information collected in the review suggests that most of the staff who had teaching positions in the various projects had appropriate professional qualifications, mainly teacher and, in a few cases, therapy training. More than half had also received some form of training in special education, though this may have involved a single course within a preservice program. The lack of suitably qualified teachers for early childhood special education is being addressed through the various courses now being offered in teacher training programs around the State. However, of more concern is the lack of appropriate training evident among the aides working in many projects. Among the 27 projects included in the review, 15 had an aide position funded by the CWSD grant. Only eight projects reported that their aides had received any training; five of these were Child Care Certificates. Several projects noted that their aides were "parents of a child with a disability." A major issue already identified concerned the need of program staff for information about aspects of program development and implementation. Here is another issue related to this topic; the need for training and development programs for all staff, but particularly aides working in early intervention projects. This need becomes particularly urgent when it is noted that some aides funded by CWSD grants appear to be providing the education component to a primarily therapy-based service. It is therefore strongly recommended that the Sub-committee support any initiatives associated with the provision of in-service or on the job training for teachers and, more particularly, aides, who lack training and experience in early special education.

7.3.3 Staff conditions of appointment

Associated with the limited, inadequate or inappropriate training of staff, particularly aides, is the problem of staff conditions of appointment.

Difficulties associated with these aspects of project operation were mentioned by a number of respondents, many of whom felt strongly that they were disadvantaged, compared to staff working in other areas of education. Much of this dissatisfaction resulted from the fact that the projects were funded on an annual-submission basis. Some of the problems related to the uncertainty of future employment, insecurity about funds being sufficient to cover salaries to the end of the year. A major grievance concerned the lack of allowances for working with children with handicaps and for assuming the responsibility of director in the project. Some of these problems could be overcome if the CWSD Program provided all project management committees with information about salaries and conditions, either from the Association of Independent Schools or from guidelines used to determine conditions within the NSW Department of School Education. This is particularly important for projects that are recently established or where the management Committee is inexperienced. It is therefore recommended that the Co-ordinating Committee provide guidelines to all projects about salaries and conditions for all staff, particularly teachers and aides.

7.3.4 Unsuitable premises

While it was observed during site visits that some projects were located in fine, new, purpose-built premises, other projects were reported to be in settings that were unsatisfactory. One issue of some importance here relates to the fact that several of the projects visited for the review were located in new buildings which had been funded by capital grants from DEET. Since project grants are made on an annual, submission basis, it is possible to envisage a situation where a project located in purpose-built, DEET-funded premises fails to have its annual application approved at a level that enables a viable service to be provided. Should continuity of funds be assured for these centres?

On the other hand, inevitably, as projects are newly established, problems will be encountered in relation to locating suitable premises for a service that has quite specific needs, in terms of toilet arrangements, access for wheel chairs and families with strollers etc. Some of these factors will be the subject of requirements by local health inspectors, licensing authorities and so on. The need for these and other similar licensing agencies to maintain a role, particularly in relation to the establishment of new programs but also in the continuation of programs already operating, is justified on the grounds that there should be some provision for community control of all services offered to young children, including those who have disabilities and are possibly more vulnerable, in their search for help, than other groups. This need is particularly important as private early intervention programs are established in increasing numbers. It is therefore recommended that the Sub-committee develop a set of guidelines for standards to be met by all projects in relation to premises in which the project is located: information should also be provided to new projects about licensing requirements, insurance, health and other safety standards.

7.3.5 Management Committees

A few respondents commented on problems associated with working with Management Committees which had a number of members who had little or no experience in the area of early childhood special education and who lacked knowledge about many aspects of the operation of such services. Community-based programs often encounter problems as the first group of parents, who struggled to establish the service, move on to other activities at the time when their own children leave the program to begin the next phase of their education. This problem is particularly evident in programs associated with children below school age: the number of years a child is likely to stay in such a program is very limited. In the light of this fairly rapid turnover in members of Management Committees, it is suggested that the CWSD Program encourage any initiatives that will provide rapid induction for new Committees, to ensure that appropriate and quality programs are maintained. In the light of this suggestion it is recommended that the Sub-committee identify procedures that could be implemented to ensure that the members of Management Committees are kept informed about aspects of the programs offered by their organisation that are associated with the delivery of high quality programs to children and their families.

7.4 Are there any issues concerning the operation of the CWSD Program that should be drawn to the attention of the Sub-committee?

The final section of the interview held with participants during site visits addressed a number of issues associated with the operation of the CWSD Program and its impact on the children involved and their families. The main issues raised in participants comments are summarised in the following points.

7.4.1 Adequacy of CWSD funds

Most of the respondents, but particularly those from small community-based programs, reported that CWSD funds were crucial for the operation of their projects. Indeed, some commented that major difficulties had been experienced when grant payments were late and a number of projects had been forced to reduce the level of service provided as a result of short falls in funding. These programs rely on fund-raising to maintain the program. One project located in a tertiary institution which had been selected for inclusion in the review had actually ceased to operate at the time that interviews for the review were being organised. A major shortfall in funds was cited as the main reason for closure. As with most other projects, there was a significant difference between funds requested and the amount allocated by the CWSD Sub-committee. The only exceptions to these funding difficulties appeared to be the projects that were located in large organisations with substantial resources.

As the number of applications for CWSD funds increases, there is a risk that the discrepancy between the sum requested by some projects and the amount actually approved becomes so large that the project is no longer viable. This is a particular risk in small projects, where staff are required to work with children and families whose needs differ widely (e.g. a child with severe cerebral palsy, a child with profound visual impairment and a child with extremely disturbed behaviour), but where there is no provision for support from other professionals and limited access to appropriate resources. Other problems resulting from appropriate resources. Other problems resulting from significant discrepancies between funds requested and those approved, include the need to reduce the level of services to an extent that children's progress is threatened; for example, a weekly playgroup with no opportunity for individual programming or direct teaching or no time available for the teacher to provide counselling for stressed parents. Comments were also made about the costs associated with project administration, which did not always reduce, though overall funding was significantly diminished. (See also letter in Appendix E) The threat of discontinuation of any CWSD funds also causes major anxiety for a number of staff. It is therefore recommended that the Sub-committee ensure that the funds allocations to projects are sufficient to enable these services to remain viable. Where appropriate, smaller projects should be encouraged to coordinate their services with other, similar programs within a district or region, to ensure that a network of support is available for staff working in isolated circumstances,as well as a larger pool of resource materials and more efficient administrative arrangements. Where funding is to cease, consideration should be given to providing a period of advanced notice: for example, a minimum of 12 months warning of termination of funds.

7.4.2 Timing of payments

An issue that is related to the adequacy of project funds concerns the timing of payments. The Sub-committee is probably aware of some problems that have arisen in recent years when CWSD payments were delayed by several months. The problems encountered, particularly by smaller projects, when payments are late contribute to the overall level of stress associated with the implementation of these services. Delays in notification of a successful application also add to the stress of both staff and families, as a result of uncertainty about the continued operation of the project in the coming year. It is therefore recommended that the Sub-committee ensure that both formal notification of funding approval and

7.4.3. Assistance with preparation of CWSD applications

A small number of respondents commented on difficulties they had experienced in completing applications for CWSD grants. It is interesting to consider that some applications are prepared by members of the Management Committee, or, in larger organisations, by an administrative officer; while in a number of smaller projects, the application is filled in by a person whose position is funded by the CWSD grant. Particular problems were encountered by staff who were newly appointed and who had had no previous experience in completing such application forms. The need for training in skills of this type should be drawn to the attention of relevant teaching institutions, and professional development activities related to this skill area should be offered.

CWSD Program staff should continue to offer support around the time that funding applications are made, particularly to projects that are known to have had problems in previous years, or where relevant project staff are newly appointed and lack experience in this type of task. In addition, care should be taken to make application forms easy to follow and simple to complete. It is recommended that the Sub-committee ensure that assistance and, where necessary, training are provided to help project representatives complete CWSD funding applications and that the forms are easy to follow and simple to complete.

7.4.4 Integration of Early Special Education and CWSD Programs

Two respondents raised the issue of overlap between the CWSD and the Early Special Education Programs. Reference has been made to problems associated with the age at which children can participate in CWSD projects (i.e. under school age), to issues in identification of children whose disabilities are severe rather than mild or moderate in nature, and to problems associated with the changing nature, of children's level of functioning, particularly as a result of effective intervention. Where children with disabilities or impairments are considered to be ineligible for participation in CWSD intervention. Where children with disabilities or impairments are considered to be ineligible for participation in CWSD projects (i.e. disability not considered to be severe and/or above the age at which school placement is available: 3-4 years in some educational services), it is likely that they will be eligible to take part in projects funded under Early Special Education guidelines (i.e. disability mild or moderate in nature, age 0-6 years), and, in fact, a number of early intervention services receive funding from both elements of the Special Education Program (i.e. Early Special Education and CWSD). This anomaly could be overcome if the two program elements were amalgamated, to allow for some element of program funds to be earmarked for services providing educational programs for children with severe disabilities, but with greater flexibility to allow for variations in funding allocations across the two program elements, in response to changing community needs. Some projects use funds from both CWSD and Early Special Education to fund a single position and find it difficult to separate the two roles. In addition, several respondents indicated that they found it distressing for some families to have to identify their children as severely disabled. The amalgamation of the two programs would overcome these problems.

There is some evidence to demonstrate the impact of changes in educational provision within generic services for students with severe disabilities over the period that the CWSD Program has operated. For example, at the time that the CWSD Program was reviewed by Ferguson and Ward (1986), all of the students participating in funded projects were in the age range 5-16 years; children below the official school age were not eligible to participate. However, these eligibility requirements were changed in 1983, allowing funds to be allocated to projects catering for children with severe disabilities in the age group 0-6 years and, by 1989, a major percentage of children identified in annual submissions were in the preschool age group. This represents a major shift in the age focus of the project and provides strong grounds to support consideration of an amalgamation of the two programs.

Provision for services for the small numbers of children with severe disabilities who are of school age (6-18 years) who do not have access to appropriate educational services would remain within the responsibility of the new program. It is therefore suggested, that the Sub-committee consider amalgamating the two programs concerned with young children with disabilities to a single program, with a component to be earmarked for projects providing services for the priority areas of children with severe disabilities in the years prior to school entry and for students in the 0-18 years age range who are denied access to appropriate educational services as a result of severe disability.

In the following, final chapter, a brief review of the main points raised in this report is presented and some concluding comments are made.

CHAPTER 8

SUMMARY AND CONCLUSION

In the first chapter of this report, four questions were posed for which answers would be sought in this review. In the following chapters of the report, information was presented from material collected from both CWSD Program records and interviews assoicated with visits to selected CWSD projects. A summary of the four questions and the answers that derived from the material assembled during the review is set out below. This is followed by a concluding comment.

8.1 Summary

1. Who is receiving services through CWSD funds?

Children mainly in the age range 24-48 months living at home in locations varying from inner metropolitan suburbs to isolated regions of the State are major recipients of CWSD funded services. On the basis of information reported in an earlier review (Ferguson & Ward, 1986), it appears that fewer CWSD projects are being provided for children in residential care settings than previously, probably, in part, as a result of an overall reduction in the number of children with severe disabilities in the age group 0-6 who are living in these types of facilities. An increase in the provision of access to generic educational services for those children who do live in long-term care may also be reflected in this change.

There is no information in this review about the extent to which all the children who are eligible to participate in CWSD projects are actually involved, but comments made by staff in some projects drew attention to the need to ensure that such children do receive appropriate educational programs if they are attending long day care or child care centres. In addition, steps should be taken to ensure that children from families who do not speak English as their first language or from Aboriginal backgrounds have access to available programs. When consideration is given to terminating the payment of CWSD funds to a previously funded service, account should be taken of an alternative source of educational programming that is available to the children involved.

2. What type of programs are being funded?

A major proportion of CWSD funds support projects initiated by community groups and, in some case, staff from generic services or associated charitable organisations. Most of these projects provide educational programs in the context of early intervention. A few are based in residential institutions or are attached to therapy services. The majority operate from a centre but some projects also have a home-based component. All appear to use appropriate assessment procedures and to provide effective teaching programs for children in a variety of individual and group contexts.

Some problem areas were identified in the review. For example, parents are usually well informed about the programs provided for their children and, in some projects, are actively involved in their implementation. However, attention needs to be given to the level of parental involvement in some programs. Teachers working in the CWSD projects are, in the main part, appropriately trained but there is a strong need for on-going staff development. Aides appear to be much less well prepared for their duties, and some attention needs to be given to the training needs of these staff. Problems in conditions of appointment, security of tenure and career options result in increased pressures on staff and in time, will probably cause a relatively high level of staff turnover. Other areas of difficulty identified in some sites include inadequate buildings, poor equipment and other resources for newer and more isolated projects, inexperienced management committees, difficulties in establishing effective working relationships with other agencies, including therapy and developmental disability teams and related early childhood services.

Other areas which may need attention include the need for an overall increase in provision for parent support and counselling, as well as for inservice-type programs to help parents acquire the skills that they will need as their children progress through the various levels of the education and social services systems. Some more detailed study may also be needed to examine the extent to which programs are being implemented through a genuine transdisciplinary approach, with full integration of therapy and educational services. Information collected in the review is not clear on the extent to which such a model is being implemented in projects supported by CWSD funds.

3. How important are CWSD funds to children and their families?

The material collected for this review provided strong evidence to support the assertion that the CWSD Program is very important to the children who participate in projects and their families. Most comments suggested that without the CWSD funded projects, the children would have no access to appropriate educational programs until they were old enough to be enrolled in a special class. While it must be acknowledged that, in time, these services will be incorporated into programs offered within the regular school system, for the immediate future CWSD funds will be required to ensure that these crucial programs are available for the children at an early stage in their development.

On the basis of current knowledge in the area of early education for children with special needs, the programs that are being provided through CWSD funds appear to be effective. However, as knowledge about the learning needs of these children increases and information about alternative approaches becomes available, the CWSD Sub-committee should give some support to projects that provide an opportunity for both parents and professionals to evaluate new or controversial solutions to the educational needs of this group of children. The CWSD Program has been one of the main stimuli for the introduction of educational programs for a severely disadvantaged group of children and it should maintain this seeding function by providing some support for exploration of new, alternative or controversial approaches to the learning needs of the target group of children and their families.

4. What issues were identified that should be drawn to the attention of the CWSD Sub-committee?

The main difficulties identified during the review concerned aspects of the administration of the CWSD Program, including the confirmation of funding, the adequacy of funds granted to individual projects, the timing of payments and clarification of eligibility requirements. Probably the most important issues to be identified concerned staff, conditions of employment and, more particularly, the need for ongoing professional development and inservice activities. Undoubtedly, the quality of programs is dependent on the knowledge and skill of the staff who implement them; the CWSD Program needs to ensure that adequate support is provided for activities that will increase staff skills.

Another area that should be considered by the Sub-committee concerns the needs of parents; for information and skills to help their children now, for support in terms of the difficulties to be encountered within the family group, and for information and skills that will be required to ensure that their child has access to high quality and appropriate services in the future. This aspect of project functioning should be supported and more fully developed, if the long-term needs of families are to be adequately addressed at this early stage in the development of the child.

CONCLUSION

Over the last decade in New South Wales, one of the most exciting areas of development in the field of early education, in general, and in educational services for children with disabilities, in particular, has been the expansion of services for children in the age range from birth to school entry. When Betty Watts and her team surveyed early intervention services in this State in 1979-80 (Watts et al, 1981) few programs were identified. By 1989, the number of such programs had increased beyond any level that could have been predicted by Watts and her team. Much of this expansion can be credited to the funds that were made available by the Commonwealth Government, through the Special Education Program elements that were concerned with the needs of young children with disabilities. By 1990, most families in New South Wales can have access to some form of early intervention at a location that is reasonably close to home. These services are generally of high quality, with appropriately trained staff and reasonable resources.

The provision of comprehensive educational services for children with mild to severe disabilities, from birth or age of identification, must have a major impact on the programs and services required for older disabled groups, as the developmental levels achieved by children in their early years are increased. It is hoped that the initiatives begun through programs such as the CWSD will be maintained and that children with disabilities and their families will continue to have access to quality services, implemented by enthusiastic and dedicated teams. The CWSD Program has had a vital role to play in these developments and should continue, through its funding arrangements, to support this crucial area of service in the future.

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APPENDICES

A. List of sample sites, plus copy of original list

B. Interview Schedule

C. Statement of Duties and Responsibilities of Staff

D. Sample of program aims

E. Letter

F. Map

APPENDIX A

List of Sample sites,

plus copy of original list

List of Centres Surveyed:	Program Number
Western Region	
Gulgong Preschool E.I.	1
Little Learners (Forbes)	2
Lithgow Early Intervention Program	3
Orana E.I. Program (Dubbo)	4
Orange District E.I. Program	5
Cowra Early Intervention Group	6
North Western Region	
Moree District Hospital	7
South Western Region	
Wagga E.I. Challenge Foundation	8
North Coast Region	
Coffs Harbour E.I. Program	9
Ballina E.I. Program	10
Jumbunna Community Preschool (Casino)	11
Summerland E.I. Program (Lismore)	12
Central Coast	
Hunter Prelude E.I. Centre (Kurri Kurri)	13
Yarran E.I.Program	14
Western Sydney Metropolitan Area	
Hawkesbury Combined Services (Stimulus, Greenhills and Windsor Pres. Preschool)	15-17
Thurina E.I. Prog. (Keymer Child Care Centre, St Marys, Doonside Preschool & Grantham Hts Child Care Centre, Seven Hills)	18
Sydney Metropolitan Area	
St Anthonys Long Day Care Centre	19
Frances Fisk Long Day Care	20
Autistic Association of NSW	21
Spastic Centre of NSW	22
Bexley Therapy Centre, St George & Sutherland, E.I.	23-24
Grosvenor Hospital	
Allowah Babies Hospital	26
Bambi Nursing Home	27

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Ph: (02) 805-8694
No. of Child. -

Sr Jennifer Brett
Moree District Hospital
P O Box 138
MOREE NSW 2400
* Project Boomi/Mgundi
* Moree E.I. Program
Ph: (067) 52-9222
No. of Child. - 4 Boomi
No. of Child. - 14 Moree

Ms R. Campbell
Narrabri Com. Health Centre
P O Box 243
NARRABRI NSW 2390
Ph: (067) 92-1522
No. of Child. - 4

Ms N. Bosler
Narrabeen Comm. Learn Cent.
Pittwater Road
NTH NARABEEN NSW 2101
* Grant Hibbard
Ph:
No. of Child. - 1

Mr J. McCreadie
Orana E.I. Project
P O Box 865
DUBBO NSW 2830
Ph: (068) 81-1324
No. of Child. - 26

Ms Judy Dwyer
Orange District E.I.
P O Box 644
ORANGE NSW 2800
Ph: (063) 62-8981
No. of Child. - 14

Ms Jan Manners
Department of Education
P O Box 143
BATHURST NSW 2795
* Orange Conference
Ph: (063) 31-9741

Lesley Burch
Sinclair Place
Moree Street
INVERELL NSW 2360
Ph: (067) 22-11180
No. of Child. - 1

Ms H. Lunn
Spastic Centre
Metropolitan Clinics
189 Allambie Road
ALLAMBIE HEIGHTS NSW 2100
Ph: (02) 451-9022
No. of Child. - 81

Sr J. Wilson
St Anthony's Long Day Care
6 King Edward Street
CROYDON N;SW 2132
Ph: (02) 747-5782
No. of Child. - 17

Dr Doherty
Student Support Services
Department of Education
P O Box 6000
PARRAMATTA NSW 2150
* 2 programs 1. Consultant
2. RSU
Ph: (02) 633-0400

Mr T. Limbert
Summerland E.I.
P O Box 398
LISMORE NSW 2480
Ph: (066) 21-6421
No. of Child. - 14

Ms Jacinta Wall
Tamworth Base Hospital
P O Box 83
TAMWORTH NSW 2340
* 2 progs. 1. T.B.H. Health
2. T.B.H. D.D.S.

Ms R. Hodges
Thurina E.I.
Marayong Baby Health Centre
Lot 22 Quakers Road
MARAYONG NSW 2148
Ph: (02) 622-5396
No. of Child. - 19

Prof. V. Ramsden
School of Electrical Engin.
University of Technology
P O Box 123
BROADWAY NSW 2007
Ph: (02) 2-0930

Mr S. Jaques
Wagga E.I. Challenge Found'n
P O Box 280
KOORINGAL NSW 2650
Ph: (069) 25-3422
No. of Child. - 17

Ms Ann Maree Kelly
Yarran E.I.
C/- Mt Penang
23 Ashton Street
KARIONG..ENTRANCE NSW 2261
Ph: (043) 40-1343
No. of Child. - 8

Ms Barbara Wallace
Yalbillinga P.S. (SSP)
Salamander Street
COFFS HARBOUR NSW 2450
* Joe Hammond
Ph: (066) 52-3533
No. of Child. - 1

APPENDIX B

Interview Schedule

Questions for
Children with Severe Disabilities Program (CWSD) Review

(Note: Not all questions are appropriate for all programs included in the survey).

1. BACKGROUND INFORMATION

1.1 Does CWSD fund all or part of your programme?

a) If yes please describe the total service.
b) If no please indentify what part of the service is funded by CWSD.

1.2 Could you briefly describe the project that is being funded by CWSD in 1989?

1.3 What are the broad objectives of the project?

1.4 How many children participated in the project in 1989 and approximately how old are they now?

Ages (months	No. of children
under 6 months	
6 - 11	
12 - 23	
24 - 35	
36 - 47	
48 - 60	
Over 60 months	
Total	

1.5 What are the primary disabilities of the children?

Primary disability		No. of children	Level of Disability		
			Mild	Mod.	Severe
Intellectual	a) Downs				
	b) Non-Downs				
Physical					
Hearing					
Vision					
Language					
Behavioural					
Multiple					
Other (please specify)					

1.6 Are any categories of disability excluded from the programme?

1.7 What is the average time children spend on your programme's waiting list?

1.8 How are children selected to take part in the project?

1.9 Who refers children to the project?

2. ASSESSMENT

2.1 On entry to the programme, what assessment procedures are carried out?

2.2 On what broad skill areas are children in your programme assessed?

2.3 Is the testing completed in one session, or do you assess the child using several session?

2.4 Who carries out these assessments?

2.5 Which disciplines are involved in the assessments?

2.6 What factors determine the disciplines that take part in assessments?

2.7 Where are the assessments carried out?

2.8 How often is a child's progress assessed?

2.9 What type of information is collected on each child?

2.10 What tests or assessment procedures do you use?

2.11 What records are kept of assessment information?

2.12 Do assessments include direct observation of children?

2.13 If direct observations are carried out, typically how many and where are they carried out?

2.14 What roles do parents typically play in their children's assessments?

2.15 Do parents normally observe assessments being carried out?

2.16 Are parents informed of the results of assessments?

2.17 How are parents informed? - orally or in writing?

2.18 Is anyone else informed about assessment results?

2.19 Do you assess individual families strengths and needs?

3. CURRICULA

3.1 What role do assessments play in each child's programme?

3.2 Are specific teaching objectives identified for each child?

3.3 How are these objectives identified?

3.4 Do you develop an Individualised Educational Programme for each child? If so, who is involved in the process?

3.5 To which areas of the curriculum do the objectives relate?

3.6 What form of curricula does your program employ?

3.7 What curricula resources do you have available to your programme?

3.8 What types of programmes are included in the teaching program?

3.9 What do you try to achieve with the activities you carry out with the children?

3.10 Does your programme includes activities in which tasks from different developmental skill areas are integrated? e.g. Motor, cognitive, communication, social-emotional and self help skills. Give examples.

3.11 Where does teaching take place?

3.12 Are children encouraged to practice new skills in other situations? Give examples.

3.13 What opportunities do you provide for incidental teaching?

3.14 What records of teaching programmes are kept? -

a) assessment
b) current daily goals
c) long term goals
d) progress report and information

3.15 Are parents involved in the identification of objectives?

3.16 Are parents involved in the teaching process?

If yes

a) Where does this take place?
b) What types of activities are they involved in?

3.17 Are parents informed about their child's programmes and progress? How?

3.18 How do you relate the activities for particular children in your programme to the family's goals for their children?

3.19 In what ways does your work with children in your programme fit into their family life?

3.20 What work do you do to enhance parent-child interactions?

3.21 What is your programmes philosophy regarding unstructured play?

4. INTEGRATION

4.1 Does your program include specific goals and activities designed to prepare children for integration? Please give examples.

4.2 Does you program encourage or arrange for some or all children to take part in activities with children who are not handicapped?

	Encourage This		Arrange This	
	All	Some	All	Some
	Children		Children	
1. Attend regular pre-schools day care, playgroup etc. on a part time basis.				
2. Arrange for non-handicapped children to attend your program.				
3. Arrange excursions to use facilities in the community.				

4.3 What is your programme's broad philosophy regarding 'integration' and 'normalisation'?

4.4 Where is this philosophy stated?

5. CULTURAL SENSITIVITY

5.1 In what ways is your programme adapted to the ethnic backgrounds of children in its community?

5.2 In what ways are the staff or volunteers employed in your programme qualified to be sensitive to the different cultures served by it?

5.3 Do you use translators to communicate with families who are not fluent in English?

6. TRANSDISCIPLINARY APPROACHES

6.1 How is professional responsibility for individual families determined in your programme?

6.2 Does your programme offer or have regular access to an appropriate range of professional assistance?

7. PROGRAMME EVALUATION

7.1 Has your programme been evaluated internally? State whether the evaluation is formal or informal, and who performs the evaluation.

7.2 How does the organisation controlling your programme review philosophies, policies and practices?

7.3 How is the impact of your programme on the clients evaluated?

7.4 What form of long-term follow-up monitoring of its clients is undertaken by your programme?

8. PARENT-PROFESSIONAL RELATIONSHIPS

8.1 How would you describe your programme's views on the parent-professional relationship?

8.2 What is your programme's practice with regard to parent access to records on individual children?

8.3 Does your program concern itself with working in childrens homes? If **yes**, please describe.

9. PARENT COUNSELLING AND SUPPORT

9.1 How does your programme take account of the needs that some parents and other family members have for systematic individual or group counselling?

9.2 Does your programme refer parents or other family members on to other agencies if it is considered they would benefit from counselling?

9.3 Is there a parent-to-parent Support-Group in your area?

9.4 Does your programme take steps to inform parents about the existence and functions of this organisation?

9.5 Does your programme put parents in contact with each other in any other informal ways?

9.6 What assistance does your programme give to its parents regarding their entitlements to benefits, allowances, etc.?

10. INTERAGENCY COORDINATION

10.1 What role does your programme play with other agencies in coordinating services for young handicapped children?

10.2 What role does your programme play in planning future developments of services for young handicapped children in your community?

10.3 What are the usual procedures followed by your programme when its children move on to another pre-school facility or to school?

11. ADVOCACY

11.1 Does you programme offer training courses for parents?

11.2 How often have these courses (if any) been offered during the past three years?

11.3 What is the content of these courses?

11.4 Have the staff on the programme taken public positions on issues to do with the rights of their clients?

11.5 What is your programme's broad philosophy with respect to the rights of young children with disabilities?

12. STAFF TRAINING

12.1 What pre-service training have the professionals on your programme received?

12.2 Do your advertisements for staff vacancies and your written job specifications specify the kind of training required for employment?

12.3 What in-service training does your programme offer for its staff?

12.4 What professional conferences on early intervention or in their discipline areas have the programme's staff attended over the past 12 months?

12.5 How does your programme induct new staff members (including volunteers)?

12.6 What management education courses have staff attended during the past 12 months?

12.7 What opportunities for career advancement are available within your programme/organisation?

12.8 Do you consider that your working conditions are satisfactory? If not please specify problem areas.

12.9 To what extent do the salaries and conditions of service of the programme's staff relate to their qualifications and responsibilities and to persons with similar qualifications and responsibilities employed in other services?

13. LOCATION AND PHYSICAL ENVIRONMENT

13.1 Does your project operate in a centre or is it home based?

13.2 If it is centre-based are home visits made; how often? By whom?

13.3 How does the appearance of your centre compare with other pre-school or child care settings in your community/area?

13.4 If you programme has a child care/day component, does it have a current license?

13.5 What physical adaptations have been made to your centre to take account of various disabilities among the children?

13.6 How close is the centre to potential clients?

13.7 Does the centre provide transport for its clients?

13.8 Is the centre on a public transport route?

13.9 Does the centre have access to a toy library?

14. ADMINISTRATION

14.1 Does your programme have a Management Committee? What is its composition?

14.2 If not please describe what form your Management takes?

14.3 What system of records does your programme keep on individual children?

14.4 In what ways does your programme keep its parents informed about what it is doing?

14.5 Does your programme charge parents any fee for its services?

14.6 Are parents reimbursed financially for transport costs incurred by their participation in the programme?

14.7 What procedures do you have for checking the special equipment (aids and appliances) used by children?

14.7 What procedures do you have for checking the toys and teaching equipment used in your programme?

15. OVERVIEW OF CWSD PROGRAM

1. How did you first learn about the CWSD program?
2. How important are CWSD funds for the operation of your program?
3. What would happen to your CWSD project if funds did not continue to be available?
4. What are the major strengths of the CWSD program?
5. What do you see as its major weaknesses?
6. What changes would you like to make to the program?
7. What are the most successful aspects of the project?
8. What are the least successful aspects?
9. Are the funds you receive from CWSD adequate?
10. What are your major difficulties in implementation CWSD funded projects?
11. How do you usually overcome these difficulties?
12. Have you received assistance from the CWSD program staff in relation to implementation of any project?
13. What type of assistance is most useful?
14. What has been the major impact of CWSD projects on the children in your program?
15. What has been the major impact on families?
16. Any other comments you wish to make.

APPENDIX C

Statement of Duties

and Responsibilities of Staff

DUTIES AND RESPONSIBILITIES

DIRECTOR

TEACHERS

CHILD CARE AIDES

CLERKS

HELPERS

DIRECTOR

- To plan, with all staff members an effective programme for each child attending the Centre
- To keep a waiting list of children
- To decide, with staff members, when a child needs to move on to another service/placement
- To supervise and organise duties of staff
- To ensure that appropriate records are kept
- To arrange staff meetings to ensure staff development and smooth running of the Centre
- To ensure regular maintenance of materials and equipment
- To prepare monthly and annual reports and attend Committee meetings
- To complete forms for FACS, DEET
- To act as a resource person to families
- To participate in selection of staff
- To Liaise with Committee
- To ensure that the Centre establishes a network of contacts in the community
- To liaise with transdisciplinary team
- To use Interagencies as the need arises

TEACHERS

- To plan in association with the Director appropriate Individualised Educational Programmes and group sessions to meet specific short and long term objectives for each child
- To take part in and have input into staff meetings and staff development
- To fulfil duties as acting Director as required
- To oversee the direction and organisation of any staff or volunteers/students under her supervision
- To keep developmental records
- To be responsible for preparation of materials for individual and group sessions
- To report to the Director on any matters affecting the smooth running of the Centre
- To attend Committee meetings as required.
- To assist with the organisation and educational input for parent meetings/groups
- To attend conferences and other courses as appropriate
- To maintain continuous professional involvement with the child's family
- To alert the Director on matters pertaining to family dynamics to encourage liaison with other agencies e.g. Respite Care, counselling
- To inform the Director of needed equipment and repairs to toys etc.
- To liaise with other professionals via verbal and written reports
- To contribute to cleanliness and tidiness of Centre as required
- To act as a resource person to families

CHILD CARE AIDES

- To work with the Director and/or teacher to ensure the smooth running of the Centre
- To participate in the preparation of programmes and planning for individual needs
- To assist with recording children's development in group sessions and plan for on-going development
- To attend staff meetings as required
- To ensure activities are prepared in advance of each session
- To contribute to the cleanliness and tidiness of the Centre
- To inform the Director/teacher of equipment and supplies needed
- To help with minor repairs to toys
- To be responsible to the Director for implementation of areas of group sessions
- To be responsible for groups of children as directed
- To take over some of the duties of the teacher as required
- To oversee the direction and organisation of any students or volunteers working at the Centre
- To catalogue new equipment
- To organise bi-monthly Newsletter

CLERKS

- To accept and receipt fees
- To balance and bank monies received
- The typing and posting of mail and keeping of stampbook
- To inform the Director/President regarding payment of fees
- To take information for new referrals
- To type, duplicate and file information for staff and Committee
- To order equipment/supplies as directed
- To prepare information for Government Departments e.g. type submissions
- To arrange appointments for children involved with trans-disciplinarian team

HELPERS

- To work with staff to ensure smooth running of the Centre
- To participate in the preparation of materials for individual and group sessions
- To help clean Centre after group sessions
- To assist with recording children's development during group sessions
- To attend staff meetings as required
- To contribute to the cleanliness, maintenance and tidiness of Centre
- To inform staff of equipment and supplies needed
- To supervise siblings of children attending Centre for individual sessions e.g. assessments, physiotherapy
- To assist clerk to balance monies and prepare for banking
- To help look after any pets at the Centre
- To maintain orderliness in storeroom for easy access to toys and gross motor equipment
- To assist staff implement group sessions
- To help catalogue new equipment
- To help with minor repairs to toys

PROJECT RULES

Nominations of candidates for election as office-bearers of the Project or as ordinary members of the committee -

(a) shall be made in writing, signed by 2 members of the Project and accompanied by the written consent of the candidate (which may be endorsed on the form of nomination); and

(b) shall be delivered to the Secretary of the Project not less than 7 days before the date fixed for the holding of the annual general meeting at which the election is to take place.

Any casual vacancy occurring among the office bearers may be filled by the Management Committee and the person so appointed to fill such a vacancy shall hold office for unexpired term of the member so replaced.

9. DUTIES OF THE MANAGEMENT COMMITTEE

The responsibilities of the Committee include:

a) The determination of policy consistent with Objects of the Project

b) The financial management of the services

c) The appointment of staff, including relief

d) The payment of award wages, and fees for services rendered to the Project

e) The conduct of the services in accordance with the Child Care Agreement and State and Local regulations

f) The insurance of the buildings, public risk, staff and property

g) The payment of rates (or exemption)

h) The payment of accounts

i) The preparation of budgets and setting of fees

j) The application for State and Federal grants

k) The organisation of publicity for the services

l) The compilation of necessary forms and records

m) The organisation of emergency medical and dental care for the children if required

n) The initiation of liaison with other community and Social Welfare groups and government and semi-government agencies

o) The preparation of reports to funding bodies

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APPENDIX D

Sample of Program Aims

Summerland, Gulgong, Ballina, Hunter Prelude

AIMS

1. To provide an early intervention program for children aged 0-5 years who have developmental delay or learning difficulties (S.G.H.B).
2. To prepare children with such problems for integrated school education (S.G.B.).
3. To help the children develop to their maximum potential (S.B.H.).
4. To provide support for parents and to assist families to accept and respond to their child in a positive way (S.G.H.B.).
5. To work with parents in devising a house program (S.B.H.).
6. To employ a transdisciplionary approach and to actively seek assistance from professionals, such as psychologists, therapists and pediatricians, to be provided direct to the families at the Centre.

SUMMERLAND

AIMS

To help the children develop to their maximum potential in all learning areas, by assessing the individual child's needs and organising an appropriate teaching program, in conjunction with the parents - either home, centre, preschool or combination. House based visits are made to assist the family in planning learning activities and to utilise appropriate resources in the community.

To assist families to accept and respond to their child in a positive way, by maintaining a close liaison with the family support group to facilitate opportunities for parents to meet other parents and share their knowledge and experience.

To work closely with other professionals in the area and coordinate their services, by consultancy/liaison and referral whenever appropriate.

To integrate the children into the normal preschool setting, by provision of group programs which focus on the importance of play and the acquisition of requisite skills for successful integration into preschool.

To ensure appropriate placement in other educational establishments when the child leaves preschool.

FUTURE PLANS Increased or expanded

- Respite care program
- Parent education
- Social support for parents
- Level of staffing
- Community awareness
- Funding and fund-raising
- Integration process

BALLINA

AIMS

To provide early intervention to help babies and children to reach their full potential as human beings.

Services provided for these aims:

Educational playgroups at the centre with teacher and visiting therapists.

Working with developmentally delayed children in their homes

Working with these children in preschools as a step towards integration.

Parents support and counselling. Coordination of health and education services for families of children with special needs.

A strong parent support group has been formed with objectives as set out in constitution.

GULGONG

AIMS

To provide an early intervention program catering for children aged 0 to 5 years.

To help children with developmental problems prepare for school education by working with children when they are young, so that problems in later school life can be more easily dealt with or overcome.

To provide support for parents by sharing ideas on child management and development.

Services provided

Playgroup: two sessions a week, with time spent in free play and in structured teaching, with children receiving individualised instruction in all areas of development to suit their own special needs. There is cooperation with therapists, psychologists, the training agents, and with parents.

HUNTER

AIMS

To provide an Early Intervention program to develop each child's abilities across all developmental areas, with individualised education programs short and long term objectives.

To encourage parents top provide input and feedback and to enable them to use strategies to encourage appropriate play skills, cognition and language in the most natural settings possible.

To integrate developmental skills in planned and unplanned play situations to facilitate generalisation.

To employ a transdisciplinary approach, providing professional services direct to families at the Centre.

To provide a home and/or centre-based service to meet the particular needs of families.

To facilitate parent-to-parent support and to encourage the child's social development in group settings with both disabled and non-disabled peers, by organising weekly group sessions.

APPENDIX E

Letter

NSW Early Intervention Association

46 Hercules Street
Chatswood NSW 2067
Telephone (02) 412 2022
Ext. 254

NEWSLETTER

NUMBER 20 AUGUST 1990

LETTERS TO THE EDITOR

Dear Editor,

During 1988 and 1989, Ballina Early Intervention received funding under the Commonwealth Special Education Program. The money received was spent on teachers' wages.

Some months ago a letter arived telling us this funding was to be cut out. After some intense lobbying, one-third of our 1989 funding was restored. This event raises a number of issues which I would like to share with members of the Association.

The Administrative Guidelines for the Special Education Program clearly state that funding cannot be guaranteed beyond one year. Given that many children in Early Intervention Programs have handicapping conditions that can at best only be alleviated (not cured in the medical sense) where is the economic or educational sense in such a policy? It is often necessary for children to receive Early Intervention Services for some years. The genius who devised this method of funding needs a good lesson in the realities of special education. It is a policy worthy of banana republics.

What is the role of our Association in helping members fight funding cuts? In the last two issues of this Newsletter, not a single word was written about the many Early Intervention programs which lost funding from the Special Education Program. Instead we read what a fine job the members of the numerous committees which allocate the Program's funds are doing. Comrades, with respect, who cares? The Association's executive must take a more public stance on the piddling amount of money available under the Program. They, and we, must fight tooth and nail for the rights of the families we work with. I am aware that the Association is a small organisation that does not have full-time field workers or lobbyists. Perhaps member organisations should think about a special levy to fund a dynamic lobbyist to take our case to the media. The media is where this battle for improved funding must be fought.

Our members who serve on the committees that allocate the Special Education Program funds are participating in a process that is resulting in lower quality of service delivery. Why do we participate in this farce? Of course the executive may trot out the increasingly tiresome argument that funds are limited. Funds are limited because the executive and the rank and file, including myself, have obviously not done enough to convince Governments of the importance of our work.

May I suggest that at the next Association conference in October extra time should be allocated to devise workable, militant strategies to confront governments and the general public with our plight. Any member who thinks I am getting over-emotional about all this might be right, but your program might be next.

Bernie O'Neill
Ballina Early Intervention

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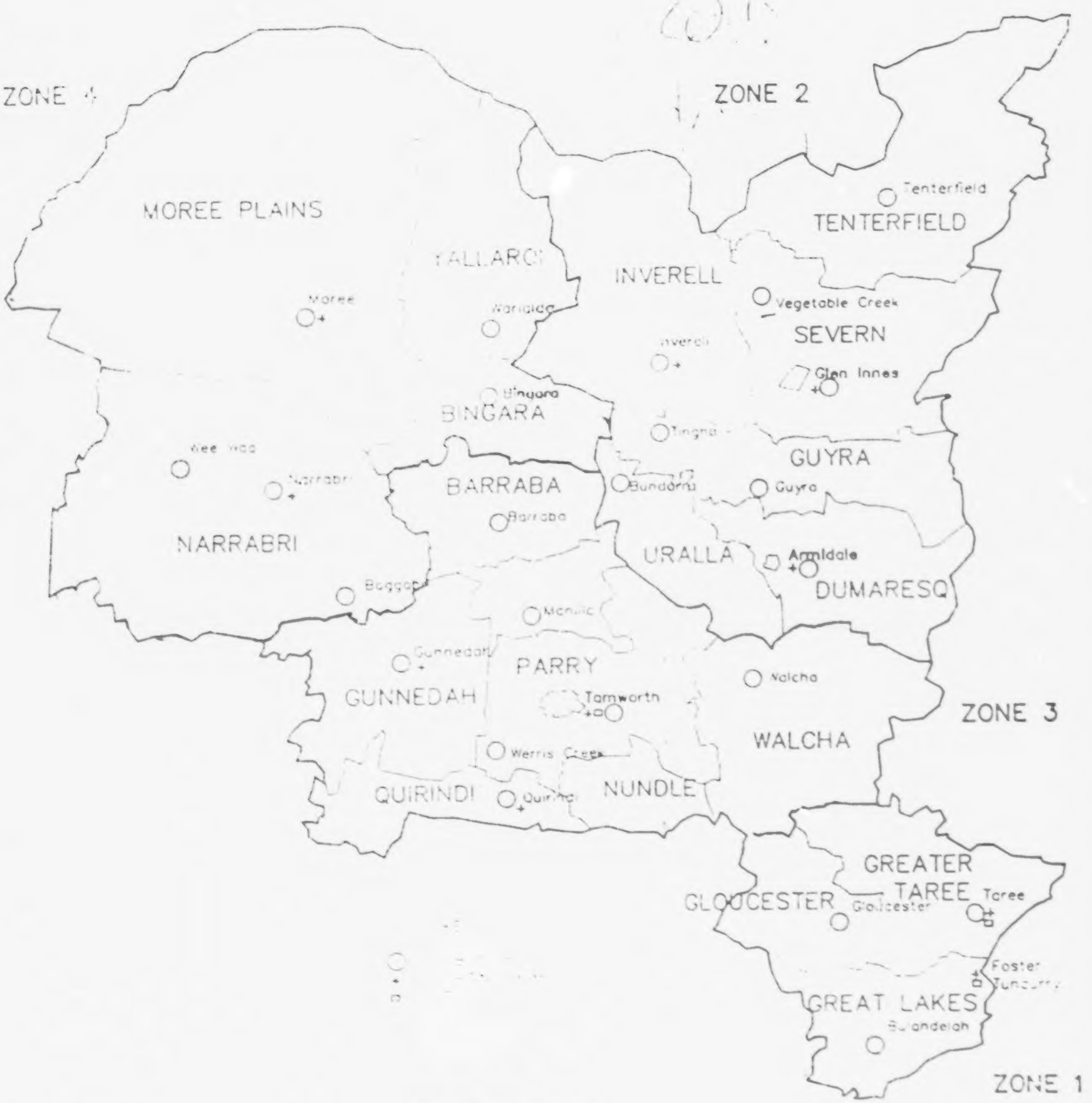
APPENDIX F

Map

REGIONAL MAP



DEPARTMENT OF HEALTH

NEW ENGLAND REGION

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Geographical Location of Service Users.